

The Futility of Futility?: On Life, Death, and Reasoned Public Policy

Mark Strasser

Follow this and additional works at: <http://digitalcommons.law.umaryland.edu/mlr>



Part of the [Health Law Commons](#)

Recommended Citation

Mark Strasser, *The Futility of Futility?: On Life, Death, and Reasoned Public Policy*, 57 Md. L. Rev. 505 (1998)

Available at: <http://digitalcommons.law.umaryland.edu/mlr/vol57/iss2/5>

This Article is brought to you for free and open access by the Academic Journals at DigitalCommons@UM Carey Law. It has been accepted for inclusion in Maryland Law Review by an authorized administrator of DigitalCommons@UM Carey Law. For more information, please contact smccarty@law.umaryland.edu.

THE FUTILITY OF FUTILITY?: ON LIFE, DEATH, AND REASONED PUBLIC POLICY

MARK STRASSER*

I.	<i>IN RE BABY K</i>	506
A.	<i>EMTALA</i>	508
B.	<i>ADA</i>	510
II.	DEFINING MEDICAL FUTILITY	514
A.	<i>Futility as Treatment's Having No Effect</i>	514
B.	<i>Futility as Treatment That Is Not Beneficial</i>	516
C.	<i>Patient Goals</i>	520
D.	<i>Qualitative and Quantitative Judgments</i>	526
1.	<i>Qualitative Judgments</i>	526
2.	<i>Quantitative Judgments</i>	529
E.	<i>Hybrid Futility Judgments</i>	532
F.	<i>Death</i>	536
G.	<i>The Futility of Treating Those Who Are Upper-Brain Dead</i>	543
H.	<i>Rationing</i>	544
I.	<i>Who Defines Futility</i>	546
III.	AUTONOMY.....	548
A.	<i>Patient Versus Physician</i>	548
B.	<i>Mischaracterizations of Autonomy</i>	553
C.	<i>Humanitarian Concerns</i>	554
IV.	CONCLUSION	556

Theorists are unable to agree about how to define medical futility. Some define futility in terms of whether the treatment will have a desired effect or promote the patient's goals, however minimally defined, while others define futility in terms of whether the treatment will help a patient achieve a certain objective level of functioning. Those opting for the latter definition disagree about how high a degree of expected functioning is required before the treatment will be considered nonfutile. Some suggest that nonfutile treatment must afford the patient a chance of leaving the hospital, whereas others believe that a treatment is nonfutile as long as it may

* Associate Professor, Capital University Law School. B.A., Harvard College; Ph.D., University of Chicago; J.D., Stanford Law School. I would like to thank George Cronheim for his helpful discussions of these and related issues.

produce some benefit such as additional minutes of nonconscious life.

The futility debate is further complicated by the numerous justifications that are offered for the competing positions—for example, autonomy, best interests, and efficient allocation of resources. While it is unlikely that the debate will or even can be resolved anytime soon, the issues would be clarified and the debate furthered if theorists were more careful about the implications and nonimplications of the various positions and justifications. Further, it would be helpful if theorists would situate their futility discussions within the context of other treatment practices. Thus, when discussing whether individuals should be able to demand the care that, even if completely successful, would not restore the patient to consciousness, commentators would do well to keep in mind that other treatments, which may in fact offer patients their only hope for conscious survival, may nonetheless be denied.

Part I of this Article discusses *In re Baby K* and suggests that the reasoning offered by the district court and the criticisms of the court's decision have implications for the appropriate conception of medical futility, because they illustrate some of the common mistakes in offering an analysis of that term. Part II discusses the competing conceptions of futility and suggests that the analyses and justifications are often unpersuasive, at least in part, because they fail to situate the discussion within the context of other kinds of treatment that patients desire but are refused nonetheless. Part III addresses how futility impacts patient autonomy. As long as medical futility is defined appropriately, it is neither empty of content nor infringing upon patient autonomy.

I. *IN RE BABY K*

*In re Baby K*¹ focused national attention on the issue of medical futility.² In *Baby K*, an anencephalic child had received mechanical-ventilator treatment and was likely to need continued treatment in the

1. 832 F. Supp. 1022 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir. 1994).

2. See *Let Baby K Die in Peace*, HARTFORD COURANT, Oct. 7, 1994, at A18, available in 1994 WL 7005735 (suggesting that keeping Baby K alive "makes no ethical sense"); Karen R. Long, *Whose Life Is It, Anyway? Debate Rages on Baby K: Kept Alive for Two Years, Child Cannot See, Hear, Think or Feel*, PLAIN DEALER (Cleveland), Oct. 9, 1994, at 1A, available in 1994 WL 7230789 (discussing the lack of consensus with respect to whether treatment for Baby K would be futile); *When Care Is Futile, Let Go*, USA TODAY, Oct. 17, 1994, at 10A, available in 1994 WL 11070849 (suggesting that treating Baby K was "a tragic exercise in medical futility").

future.³ The hospital where the infant received the respiratory therapy petitioned for a declaratory judgment absolving the hospital of liability under the Emergency Medical Treatment and Active Labor Act (EMTALA)⁴ if the hospital refused to provide ventilator treatment when Baby K next experienced respiratory distress. The hospital made clear that its request was not based on financial considerations but, instead, on its belief that such treatment would be medically inappropriate.⁵ Anencephalic infants are inflicted with a disease that is invariably fatal;⁶ such infants are incapable of consciousness⁷ and are therefore unable to see, hear, or feel.⁸

While the guardian ad litem and the father of the child agreed that mechanical-ventilator treatment should not be given, the mother did not. She opposed the discontinuation of ventilator treatment both because she believed that all human life has value and because she hoped that God might decide to work a miracle.⁹

The *Baby K* district court held that federal law prevented a hospital from refusing to treat an anencephalic infant, even if that treatment would be futile.¹⁰ However, the court also suggested that the relief of the respiratory distress of an anencephalic child was not futile care.¹¹ When affirming the judgment of the lower court, the Court of Appeals for the Fourth Circuit implied that it was not relevant that the prevailing standard of medical care might not require that respiratory assistance be given to an anencephalic child, because the plain language of EMTALA required that such treatment be given in any event.¹²

3. *Baby K*, 832 F. Supp. at 1025-26.

4. 42 U.S.C. § 1395dd (1994).

5. *Baby K*, 832 F. Supp. at 1025-26.

6. See *In re T.A.C.P.*, 609 So. 2d 588, 589 (Fla. 1992) (explaining that anencephaly is "a birth defect [that is] invariably fatal").

7. See Charles R. DiSalvo, *Worshipping at the Altar of Technique: Manic Aggressive Medicine and Law*, 40 VILL. L. REV. 1365, 1365 (1995) (explaining that Baby K was incapable of any consciousness).

8. *Baby K*, 832 F. Supp. at 1025; Robert D. Cantwell, Note, *An Anencephalic Child Kept Alive Through the Fourth Circuit's Interpretation of the Emergency Medical Treatment and Active Labor Act: A "Medical Miracle" or a "Living Corpse"?*, 14 ST. LOUIS U. PUB. L. REV. 323, 323 (1994).

9. *Baby K*, 832 F. Supp. at 1026.

10. *Id.* at 1027 ("The plain language of the statute requires stabilization of an emergency medical condition. The statute does not admit of any 'futility' or 'inhumanity' exceptions.").

11. *Id.* ("The use of a mechanical ventilator to assist breathing is not 'futile' or 'inhuman' in relieving the acute symptoms of respiratory difficulty." (emphasis omitted)).

12. The Fourth Circuit explained:

[The Hospital] maintains that a requirement to provide respiratory assistance would exceed the prevailing standard of medical care. However, the plain lan-

A. EMTALA

EMTALA requires that hospitals provide stabilizing treatment to individuals who come to emergency rooms requiring emergency treatment.¹³ The Act was passed to prevent hospitals from "dumping" their patients, i.e., either denying care altogether or transferring patients without stabilizing them.¹⁴

The *Baby K* district and appellate courts held that EMTALA requires that treatment be given to nonindigent patients like Baby K.¹⁵ Arguably, that statutory interpretation was incorrect, because, as courts and commentators have suggested, EMTALA "was designed to protect the rights of indigent patients only."¹⁶ In the case involving Baby K, the hospital was not motivated by financial considerations but, instead, by the belief that treating Baby K would involve the provision

guage of EMTALA requires stabilizing treatment for any individual who comes to a participating hospital, is diagnosed as having an emergency medical condition, and cannot be transferred [W]e cannot ignore the plain language of the statute.

In re Baby K, 16 F.3d 590, 596 (4th Cir. 1994).

13. 42 U.S.C. § 1395dd(b)(1) (1994) ("If any individual (whether or not eligible for benefits under this subchapter) comes to a hospital and the hospital determines that the individual has an emergency medical condition, the hospital must provide . . . such further medical examination and such treatment as may be required to stabilize the medical condition."); accord *Baby K*, 832 F. Supp. at 1026 (interpreting EMTALA as requiring "that participating hospitals provide stabilizing medical treatment to any person who comes to an emergency department in an 'emergency medical condition' when treatment is requested on that person's behalf").

14. See Elizabeth A. Larson, Note, *Did Congress Intend to Give Patients the Right to Demand and Receive Inappropriate Medical Treatments?: EMTALA Reexamined in Light of Baby K*, 1995 Wis. L. Rev. 1425, 1431 (arguing that Congress passed EMTALA to ensure that patients receive sufficient care regardless of their financial situations).

15. *Baby K*, 16 F.3d at 596 ("[T]he plain language of EMTALA requires stabilizing treatment for *any individual* who comes to a participating hospital, is diagnosed as having an emergency medical condition, and cannot be transferred." (emphasis added)); *Baby K*, 832 F. Supp. at 1026 ("EMTALA requires that participating hospitals provide stabilizing medical treatment to *any person* who comes to an emergency department." (emphasis added)).

16. *ZaiKaner v. Danaher*, No. 489-749, 1990 WL 264721, at *2 (D. Minn. Oct. 21, 1990); accord Larson, *supra* note 14, at 1431 ("Congress passed EMTALA for the express purpose of ensuring that those who seek emergency room medical services receive adequate care, regardless of their ability to pay."); Scott B. Smith, Note, *The Critical Condition of the Emergency Medical Treatment and Active Labor Act: A Proposed Amendment to the Act After In the Matter of Baby K*, 48 VAND. L. REV. 1491, 1497 (1995) ("As the legislative history reveals, there is no question the legislative purpose behind EMTALA was to prohibit Medicare hospitals from dumping patients due to an improper economic motive."). But see *Urban v. King*, 783 F. Supp. 560, 562 (D. Kan. 1992) (mem.) ("Although the legislative history of the statute reflects a concern with the treatment of uninsured patients, the statute, itself, draws no distinction between persons with or without the means to pay for medical care.").

of (what the hospital considered) inappropriate care.¹⁷ Thus, some commentators suggest that EMTALA was simply inapplicable because the rights of an indigent patient were not at issue.¹⁸ Other commentators have argued that other federal statutes more precisely addressed the facts at issue in *Baby K* and that those statutes would not have required treatment in that case.¹⁹

One set of issues involves whether *Baby K* was rightly decided—for example, whether EMTALA was applicable or whether EMTALA was rightly interpreted. Insofar as those issues involve a dispute about congressional intent, the relevant difficulties could be resolved if Congress would clarify what it intends EMTALA to include;²⁰ for example, Congress could pass an amendment specifying that the Act is intended to apply only to indigent care.²¹

A different set of issues involves whether *Baby K* has any bearing on the multitude of situations in which EMTALA is not implicated,²² especially for those jurisdictions that limit the applicability of EMTALA to cases involving patient dumping.²³ *Baby K* might seem to

17. *Baby K*, 832 F. Supp. at 1025.

18. See Larson, *supra* note 14, at 1454-55 ("Under the indigent-and-uninsured-only rule, this case would not have been decided by EMTALA." (footnote omitted)).

19. See Cantwell, *supra* note 8, at 342-43 (suggesting that the Rehabilitation Act of 1973, 29 U.S.C. § 794(a) (1994 & Supp. 1995), and its accompanying regulations should have controlled the judgment in *Baby K*, which, in turn, should have allowed the termination of the aggressive treatment of the infant); David Zell Myerberg, Comment, *The Fourth Circuit's Baby K Decision: "Plain Language" Does Not Make Good Law*, 98 W. VA. L. REV. 397, 408-09 (1995) (claiming that EMTALA was not meant to overrule the Child Abuse Amendments of 1984, 42 U.S.C.A. § 5106g(6) (West Supp. 1997), which permit a physician to withdraw care if she determines that further care is futile).

20. See *Baby K*, 832 F. Supp. at 1027 (suggesting that the argument for an EMTALA futility exception "should be directed to the U.S. Congress, not to the Federal Judiciary").

21. See Smith, *supra* note 16, at 1530 ("Congress should amend EMTALA to protect only indigent and uninsured patients.").

22. See Erin A. Nealy, Comment, *Medical Decision-Making for Children: A Struggle for Autonomy*, 49 SMU L. REV. 133, 157 (1995) (discussing "situations that do not implicate the EMTALA").

23. See, e.g., *Stewart v. Myrick*, 731 F. Supp. 433, 435-36 (D. Kan. 1990) (limiting EMTALA to its anti-dumping objective); *Nichols v. Estabrook*, 741 F. Supp. 325, 329 (D.N.H. 1989) (holding that EMTALA applied exclusively to cases of patient dumping); *Evitt v. University Heights Hosp.*, 727 F. Supp. 495, 497 (S.D. Ind. 1989) (refusing to extend EMTALA beyond its legislative purpose of preventing hospitals from turning away patients for economic reasons); cf. Larson, *supra* note 14, at 1431 ("Congress passed EMTALA for the express purpose of ensuring that those who seek emergency room medical services receive adequate care, regardless of their ability to pay."); Smith, *supra* note 16, at 1497 ("As the legislative history reveals, there is no question the legislative purpose behind EMTALA was to prohibit Medicare hospitals from dumping patients due to an improper economic motive."). But see *Collins v. DePaul Hosp.*, 963 F.2d 303, 308 (10th Cir. 1992) (explaining that the fact that the Act was an anti-dumping bill "does not subtract from its use of the broad term 'any individual'"); *Brooker v. Desert Hosp. Corp.*, 947 F.2d 412, 414 (9th Cir. 1991)

have no implications for the issue of concern here, namely, an exploration of the concept of medical futility. Yet, appearances notwithstanding, given the court's interpretation of the Americans with Disabilities Act of 1990 (ADA),²⁴ *Baby K* may have important implications for non-EMTALA cases and for the concept of medical futility.

B. ADA

The *Baby K* district court offered another reason to reject the permissibility of refusing to treat Baby K, noting that "the ADA does not permit the denial of ventilator services that would keep alive an anencephalic baby when those life-saving services would otherwise be provided to a baby without disabilities at the parent's request."²⁵ Thus, the court argued that the ADA prohibited providing ventilator support for one infant and not another, if the basis of that differentiation was that the latter was anencephalic and the former was not.²⁶

Commentators have suggested that the *Baby K* interpretation of the ADA was incorrect; these commentators argue that the comparison was inapposite because the infant without disabilities would presumably not need ventilator support.²⁷ However, if the *Baby K* district court's interpretation of the ADA was in error, that cannot be established by simply pointing out that a person without a disability would not be in need of assistance.²⁸ That kind of argument does not help-

(stating that because EMTALA unambiguously includes nonindigents, courts need not consult the legislative history to determine coverage); *Gatewood v. Washington Healthcare Corp.*, 933 F.2d 1037, 1040 (D.C. Cir. 1991) ("Though the Emergency Act's legislative history reflects an unmistakable concern with the treatment of uninsured patients, the Act itself draws no distinction between persons with and without insurance. Rather, the Act's plain language unambiguously extends its protections to 'any individual' who seeks emergency room assistance."); *Cleland v. Bronson Health Care Group, Inc.*, 917 F.2d 266, 269 (6th Cir. 1990) (rejecting the contention that the Act only applies to indigents).

24. 42 U.S.C. § 12101 (1994).

25. *Baby K*, 832 F. Supp. at 1029. *But see* E. Haavi Morreim, *Futilitarianism, Exoticare, and Coerced Altruism: The ADA Meets Its Limits*, 25 SETON HALL L. REV. 883, 924-25 (1995) (offering a different reading of both EMTALA and the ADA).

26. *Baby K*, 832 F. Supp. at 1029.

27. *See, e.g.*, Giles R. Scofield, *Medical Futility Judgments: Discriminating or Discriminatory?*, 25 SETON HALL L. REV. 927, 942 (1995) (arguing that if Baby K "did not have her disability, she would not have needed the treatment in question").

28. Compare one court's conclusion:

[A] plaintiff must prove that he or she was discriminatorily denied medical treatment because of the birth defect and, at the same time, must prove that, in spite of the birth defect, he or she was "otherwise qualified" to receive the denied medical treatment. Ordinarily, however, if such a person were not so handicapped, he or she would not need the medical treatment and thus would not "otherwise qualify" for the treatment.

Johnson by Johnson v. Thompson, 971 F.2d 1487, 1493 (10th Cir. 1992).

fully distinguish between the kinds of cases in which the ADA will require treatment and those in which it will not. Because many futility decisions involve individuals who have disabilities,²⁹ one's pointing out, for example, that an infant without disabilities would not need ventilator support would simply provide no guidance for deciding which treatments would be futile in a whole category of cases.³⁰

Consider an AIDS patient who accidentally injures her foot. Here, the injury has nothing to do with the illness, and a refusal to treat the foot injury would be, all else being equal, a violation of the ADA, because the injury would certainly be treated if the person did not have AIDS.³¹ It would at best be unhelpful to reject the *Baby K* district court's analysis by claiming that the person without AIDS would not have injured her foot, even if one can put aside the fact that there is no reason to believe that only AIDS patients injure their feet. By the same token, even if one puts aside the fact that nonanencephalic infants may also require respiratory support (e.g., infants born prematurely),³² one will not establish the weakness of the *Baby K* interpretation by simply denying that nondisabled infants will need ventilator treatment.

The point here is not that the AIDS patient with the foot injury and the anencephalic child in need of respiratory treatment are analogous in all respects. In the former case, the foot injury would be unrelated to the disability,³³ whereas in the latter case, the ventilator treatment would be needed precisely because of the disability.³⁴ In-

29. See Mary A. Crossley, *Medical Futility and Disability Discrimination*, 81 IOWA L. REV. 179, 213 (1995) ("[I]t is quite difficult to imagine (or find in the medical literature) an example of a person for whom life-sustaining medical treatment would be deemed futile who would not also be 'an individual with a disability.'").

30. A further difficulty is that such a point may be inaccurate. See *infra* note 32 and accompanying text (suggesting that premature infants may also need respiratory support).

31. See Scofield, *supra* note 27, at 943 (contrasting "treating a person with AIDS for a foot injury" with a treatment decision "necessitated by virtue of the patient's disability").

32. See Nancy K. Rhoden, *Treatment Dilemmas for Imperiled Newborns: Why Quality of Life Counts*, 58 S. CAL. L. REV. 1283, 1293 (1985) (discussing how premature infants frequently require respiratory support).

33. See *id.* at 1299 (arguing that the nondiscrimination principle functions properly in Down's syndrome cases in part because "the life-threatening condition is separate from, and unrelated to, the handicap"); Jennifer Stokley, Note, *Withdrawing or Withholding Medical Care from Premature Infants: Who Should Decide, and How?*, 70 N.D. L. REV. 129, 138 (1994) (describing nondiscrimination as working well in the rare cases in which the handicap is unrelated to the life-threatening condition).

34. See Larson, *supra* note 14, at 1453 ("Baby K's anencephaly did cause her respiratory distress.").

deed, this distinction does not seem to have been appreciated by the *Baby K* district court.³⁵

The *Baby K* district court suggested that Baby K's breathing difficulties had to be distinguished from her anencephaly.³⁶ While that is true at least in the sense that an anencephalic infant will not always have occurrent respiratory difficulties,³⁷ the district court was wrong, at least in part, to imply that Baby K's respiratory difficulties would be analogous to the difficulties faced by an accident victim who had cancer or AIDS.³⁸ This is because the difficulties of the latter patients would not be caused by or associated with their illnesses, while the same could not be said of Baby K.³⁹ Commentators have suggested that it may be legally significant if the condition for which treatment is sought is unrelated to the underlying illness.⁴⁰

Yet, this point is less telling than it might first appear. Even if the condition is not associated with the underlying disability, this does not imply that the condition should therefore be treated.⁴¹ If futility is to have any substantive content at all, it cannot be true that conditions not associated with the underlying disability must be treated *regardless* of the patient's prognosis. Further, the mere fact that Baby K had

35. See *In re Baby K*, 832 F. Supp. 1022, 1027 (E.D. Va. 1993) (drawing an analogy between the respiratory difficulties of anencephalic infants and the respiratory difficulties of accident victims who have terminal cancer or AIDS), *aff'd*, 16 F.3d 590 (4th Cir. 1994).

36. *Id.* ("[R]espiratory difficulty . . . is the emergency medical condition that must be treated under EMTALA.").

37. See *Baby K*, 16 F.3d at 596 (explaining that Baby K can go months at a time without requiring respiratory support).

38. See *Baby K*, 832 F. Supp. at 1027 (stating that denying Baby K treatment would enable hospitals to refuse emergency treatment to patients who have AIDS or cancer because "they eventually will die anyway from those diseases").

39. See Larson, *supra* note 14, at 1453 ("The cancer or AIDS did not cause the accidental injury, whereas Baby K's anencephaly did cause her respiratory distress.").

40. One commentator has noted:

[I]f a blind person is denied a kidney transplant on account of her congenital blindness, there might be unlawful discrimination, since the need for a kidney transplant is independent of the blindness. However, if a child with a severe developmental disability is denied a surgical procedure to treat the disability, there would be no unlawful discrimination because the need for the surgical procedure arises out of the disability itself.

David Orentlicher, *Destructuring Disability: Rationing of Health Care and Unfair Discrimination Against the Sick*, 31 HARV. C.R.-C.L. L. REV. 49, 60-61 (1996); accord Mary Crossley, *Infants with Anencephaly, the ADA, and the Child Abuse Amendments*, 11 ISSUES L. & MED. 379, 401 (1996) (describing courts that have "suggested that disability discrimination law applies to medical decisions only if the condition requiring treatment is unrelated to the person's disability").

41. See Rhoden, *supra* note 32, at 1301-02 (suggesting that it may be inappropriate to treat an unrelated condition in a case involving someone who will never regain consciousness in any event).

difficulties associated with her disability would not, of itself, necessarily absolve the hospital of any duty to treat the infant. Just as an AIDS patient who has an illness associated with the disease (e.g., pneumocystis carinii pneumonia)⁴² would not be barred from receiving treatment,⁴³ so too Baby K, who had difficulties associated with her condition, should not be barred from receiving treatment simply by virtue of the nexus between her difficulties and her condition. If treating Baby K was futile, it was not merely because the condition requiring treatment was associated with her underlying disability, nor even merely because Baby K's long-term prognosis was not as good as that of a nonanencephalic infant in need of respiratory therapy. The ADA does not require that the prognosis for an individual with a disability be as good as that of a similarly situated person without the disability in order for the person with a disability to fall within the Act's protection.⁴⁴

The question at hand is not whether there should be a bar to treatment whenever the difficulties are associated with an illness. Rather, the question is when, if ever, would difficulties be futile to treat, regardless of whether they are associated with a particular illness. It seems clear that the definition of futility should rely on some basis other than simply whether the conditions are illness-related; otherwise, someone with a good prognosis might not receive treatment because her condition was associated with her illness, whereas someone with a very bad prognosis might nonetheless receive treatment because the condition was not associated with her illness.

Commentators point out a relevant difference between Baby K and an accident victim with a terminal illness: The accident victim who receives treatment may be restored to a functioning—albeit shortened—life, whereas Baby K could not be so restored.⁴⁵ The

42. See Keith Shiner, Note, *Medical Futility: A Futile Concept*, 53 WASH. & LEE L. REV. 803, 825 (1996) (describing pneumocystis carinii pneumonia as "a leading complication caused by AIDS").

43. See *id.* (explaining how Baby Rena, after being diagnosed with pneumocystis carinii pneumonia, was placed on a respirator and received artificial feeding and medication).

44. But see Kristi E. Schrode, Comment, *Life in Limbo: Revising Policies for Permanently Unconscious Patients*, 31 HOUS. L. REV. 1609, 1658 (1995) (implying that treatment may be withheld if it would be less effective for that patient than for others).

45. According to one commentator, the relevant difference is this:

An AIDS patient may tragically have a shorter than expected life span, but it is generally a fully conscious life. Further, there remains hope that a treatment of a suppressed immune system is possible. In contrast, Baby K was not able to hear, see, think, or interact with others. There is no cure that could have replaced her missing brain to provide a chance of any sort of conscious life.

Mark A. Bonanno, *The Case of Baby K: Exploring the Concept of Medical Futility*, 4 ANNALS HEALTH L. 151, 167-68 (1995) (footnote omitted).

question at hand is whether Baby K's inability to function in particular ways or at a particular level⁴⁶ would render her treatment medically futile. A separate question, though not the focus of this Article, is whether federal law would permit the nontreatment of Baby K, even if it were medically futile.⁴⁷

II. DEFINING MEDICAL FUTILITY

There is no consensus about how to define futile medical care.⁴⁸ Numerous definitions have been offered, none of which is satisfactory. Some definitions seem clearly underinclusive, others seem clearly overinclusive, while still others seem both overinclusive and underinclusive. An appropriate definition of futility neither negates the term by preventing it from doing any work nor unduly expands the term by calling treatments futile that nonetheless could afford the patient additional conscious life.

A. *Futility as Treatment's Having No Effect*

Some define futility in terms of the treatment producing no effect.⁴⁹ If a patient has a virus, for example, it will be futile to use antibiotics to treat that virus, because antibiotics do not affect vi-

46. Morreim, *supra* note 25, at 901 ("It is meaningless to speak of [Baby K's] 'opportunities' or of her 'participation' in society.").

47. See *In re Baby K*, 832 F. Supp. 1022, 1027 (E.D. Va. 1993) (suggesting that EMTALA does not have an exception for futile treatments), *aff'd*, 16 F.3d 590 (4th Cir. 1994); *id.* at 1029 (suggesting that the ADA does not have a futility exception); see also Smith, *supra* note 16, at 1532 (suggesting that the ADA would protect anencephalic infants like Baby K). But see Beth Brandon, Note, *Anencephalic Infants as Organ Donors: A Question of Life or Death*, 40 CASE W. RES. L. REV. 781, 811-12 (1989-1990) (suggesting that the federal Child Abuse Prevention and Treatment Act, 42 U.S.C.A. § 5106g(6) (West Supp. 1997), as amended, would allow withholding treatment from anencephalic infants).

48. See Bonanno, *supra* note 45, at 157 ("In general, the concept of medical futility is poorly defined and frequently misused in the clinical setting."); Council on Ethical & Judicial Affairs, American Med. Ass'n, *Guidelines for the Appropriate Use of Do-Not-Resuscitate Orders*, 265 JAMA 1868, 1870 (1991) ("Evidence suggests that terms such as *futility*, when used by physicians to express the probability of achieving a specified outcome, have a variety of potential meanings that are understood differently by different physicians."); Crossley, *supra* note 29, at 187 (discussing "the absence of consensus on how to define the term 'futility'"); Judith F. Daar, *A Clash at the Bedside: Patient Autonomy v. A Physician's Professional Conscience*, 44 HASTINGS L.J. 1241, 1246 (1993) ("[T]here is a general lack of consensus in defining what constitutes medically futile treatment.").

49. See Eric M. Levine, *A New Predicament for Physicians: The Concept of Medical Futility, the Physician's Obligation to Render Inappropriate Treatment, and the Interplay of the Medical Standard of Care*, 9 J.L. & HEALTH 69, 74 (1994-1995) (discussing situations where treatment produces virtually no effect).

ruses.⁵⁰ This criterion of futility seems relatively straightforward—as long as the treatment produces *no* effect, it cannot be claimed to be an appropriate treatment.⁵¹ Yet, even if it is obvious that treatments that produce no effect should be considered futile, that does not establish that *only* such treatments should be considered futile. Otherwise, “futility” would imply that treatments that produce *any* effect would not appropriately be so classified.⁵² For example, treating patients in a permanent vegetative state would then not be futile.⁵³ Further, treating a cut on the arm of someone who is dying might not be futile, because one would thereby be killing bacteria capable of causing an infection, even if the killing of those bacteria would have no effect on the patient’s prognosis.⁵⁴ Indeed, consider a treatment that does not extend the patient’s life and does not benefit her in any way, but only diminishes her quality of life by causing her additional

50. See *id.* (“Antibiotics, which combat bacterial infections, are ineffective in fighting viral infections.”). Along this same line of reasoning, commentators have explained: No physician would feel obligated to yield to a patient’s demand to treat pneumonia with insulin. The physician would rightly argue that (in the absence of insulin-requiring diabetes) such treatment is inappropriate; insulin might have a physiologic effect on the patient’s blood sugar, but would offer no benefit to the patient with respect to the pneumonia.

Lawrence J. Schneiderman et al., *Medical Futility: Its Meaning and Ethical Implications*, 112 ANNALS INTERNAL MED. 949, 950 (1990); accord Marc D. Stern, “And You Shall Choose Life”: *Futility and the Religious Duty to Preserve Life*, 25 SETON HALL L. REV. 997, 998 (1995) (discussing “treatments which have no effect whatsoever, such as laetrile as a cancer cure”).

51. See Robert M. Veatch & Carol Mason Spicer, *Medically Futile Care: The Role of the Physician in Setting Limits*, 18 AM. J.L. & MED. 15, 15 (1992) (suggesting that “care that produces no demonstrable effect” is clearly futile medical care).

52. One commentator writes:

By direct implication of mandating endless respirator care for anencephalic, terminally ill Baby K, we have embraced the farthest reaches of what I will call “exoticare”: virtually any cost for virtually any level of care must be shouldered for virtually any patient who has even the smallest chance of surviving or benefitting, even for a short time.

Morreim, *supra* note 25, at 910.

53. See Marcia Angell, Editorial, *The Case of Helga Wanglie: A New Kind of “Right to Die” Case*, 325 NEW ENG. J. MED. 511, 512 (1991) (“In the family’s view, however, merely maintaining [the] life [of someone who would never be restored to consciousness] was a worthy goal, and the respirator was not only effective toward that end, but essential.”); George P. Smith, II, *Utility and the Principle of Medical Futility: Safeguarding Autonomy and the Prohibition Against Cruel and Unusual Punishment*, 12 J. CONTEMP. HEALTH L. & POL’Y 1, 7 (1995) (“[T]his definition is too narrow to permit withholding or withdrawing treatment from a body doomed to existence in a [persistent vegetative state].”). But see *Conservatorship of Drabick*, 245 Cal. Rptr. 840, 856 (Ct. App. 1988) (suggesting that the focal point for someone in a permanent vegetative state should be whether the person could be returned to consciousness, rather than whether the biological vegetative existence could be continued).

54. Cf. Rhoden, *supra* note 32, at 1315 (discussing how treating an infection of a permanently unconscious infant might be required).

pain.⁵⁵ Such a treatment would not seem to be futile on the futility-as-having-no-effect view.⁵⁶ While treatments that produce no effect are clearly futile, a definition that restricts the concept to this sole criterion is clearly underinclusive.

B. *Futility as Treatment That Is Not Beneficial*

A treatment whose only effect is to increase pain would seem to be a paradigmatic example of futile treatment.⁵⁷ Rather than defining futility in terms of treatments that have no effect, it seems more accurate and complete to define the concept in terms of treatments that have no beneficial effect.⁵⁸ Indeed, the United States Supreme Court has suggested that a treatment is ineffective unless it affords some benefit to the patient.⁵⁹

It is not clear, however, that defining futility in terms of a treatment's having no beneficial effect, rather than no effect at all, will solve the difficulty suggested above. While the treatment that does not extend life but only produces pain might then be classified as futile,⁶⁰ the other two examples might still be viewed as beneficial; after all, one could argue that it is beneficial both to prevent infections and to keep someone alive who is in a permanent vegetative state.⁶¹ Indeed, one might further argue that for a person in a persistent vegeta-

55. See *In re Conroy*, 486 A.2d 1209, 1232 (N.J. 1985) (discussing a situation in which "the patient is suffering, and will continue to suffer throughout the expected duration of his life, unavoidable pain"); *In re Richardson*, 581 N.Y.S.2d 708, 709 (Sup. Ct. 1992) (discussing a case in which cardiopulmonary resuscitation would only "result in further unnecessary suffering"); Shiner, *supra* note 42, at 824 (discussing a case in which "intervention would only inflict pain on the child without improving the possible outcome").

56. The claim here is not that such a treatment would be appropriate, but merely that such a treatment would not be futile if futility is defined in terms of producing no effects.

57. But see Stern, *supra* note 50, at 1008 (suggesting that patients should be allowed to "choose to endure possibly painful, futile treatments").

58. See Judith F. Daar, *Medical Futility and Implications for Physician Autonomy*, 21 AM. J.L. & MED. 221, 221 (1995) (suggesting that medical futility implies that the "treatment will provide no medical benefit to the patient"); Lawrence J. Schneiderman & Nancy Jecker, *Futility in Practice*, 153 ARCHIVES INTERNAL MED. 437, 437 (1993) (arguing that a treatment that fails to provide a benefit is futile); Shiner, *supra* note 42, at 827 (describing, among other things, a conception of futility that includes "care that produces an effect, but offers no benefit"). But see Veatch & Spicer, *supra* note 51, at 36 (suggesting that definitions of futility are problematic insofar as they include "care that has an effect, but that clinicians believe has no benefit").

59. See *United States v. Rutherford*, 442 U.S. 544, 555 (1979) ("In the treatment of any illness, terminal or otherwise, a drug is effective if it fulfills, by objective indices, its sponsor's claims of prolonged life, improved physical condition, or reduced pain.").

60. But see *infra* text following note 71.

61. By the same token, extending the life of an anencephalic infant might be viewed as beneficial. See Morreim, *supra* note 25, at 888 ("Baby K's intermittent respirator treatments do, after all, keep her alive when she would otherwise have died.").

tive state, none of a whole host of treatments would be futile if the person's life might thereby be prolonged.⁶² Also, doing everything to keep a terminally ill person alive for as long as possible need not be viewed as futile, regardless of the patient's condition, as long as there is reason to believe that the terminally ill person's life might in fact be extended.⁶³ Further, consider a treatment that would in fact extend a life, but the only "benefit" of that extension would be that the patient would suffer.⁶⁴ Some would argue that such a treatment would not be futile because it would in fact extend life, although others would find it difficult to characterize such a treatment as anything but futile.⁶⁵

Analyses of futility are not limited to examinations of effects or benefits, however. Indeed, some commentators offer a more refined approach, in which futility is defined in terms of whether a treatment will provide a *net* benefit. Under this definition, even if the extension of life is viewed as a benefit, that benefit need not establish the nonfutility of the treatment if, for example, the only effect of that extension of life would be increased suffering for the patient.⁶⁶

When one talks about a net benefit, one is assigning relative values and weights to particular outcomes and suggesting that one outcome is beneficial to some roughly quantifiable extent and that another outcome is harmful to some roughly quantifiable extent. Such an analysis requires that some system of values be used to deter-

62. Again, this reasoning would also seem applicable to anencephaly. *See id.* at 909 ("Baby K, for example, received a respirator for respiratory distress. If her heart had failed, however, she might have needed a left ventricular assist device or even an organ transplant. They, too, could stave off her death a while longer." (footnote omitted)). *But see* Robert J. Dzielak, Note, *Physicians Lose the Tug of War to Pull the Plug: The Debate About Continued Futile Medical Care*, 28 J. MARSHALL L. REV. 733, 764 (1995) ("Treatment that cannot alter the irreversible nature of permanent unconsciousness or dependence on intensive medical care consequently cannot improve a patient's quality of life and therefore is futile.").

63. Regarding the *Baby K* ruling in particular, it has been observed:

After the *Baby K* ruling, physician decisions regarding terminally ill newborns may be controlled by the irrational beliefs of surrogates. Even if a patient is terminally ill, all care necessary to keep the patient alive may be demanded and must be provided, though it may be against the physician's best judgment.

Myerberg, *supra* note 19, at 400.

64. *See* Custody of a Minor, 434 N.E.2d 601, 609 (Mass. 1982) (describing a case in which treatment "would involve a substantial degree of bodily invasion, accompanied by discomfort and pain, and would do nothing but prolong the child's 'agony and suffering'"); Shiner, *supra* note 42, at 824 (describing a case in which "intervention would only inflict pain on the child without improving the possible outcome").

65. *See* Stern, *supra* note 50, at 1008 (discussing individuals who would "choose to endure possibly painful, futile treatments" and some commentators' reactions to such decisions).

66. *See, e.g.,* Veatch & Spicer, *supra* note 51, at 18 ("In order to establish that care is futile, the clinician must claim that even though the care predictably will have some effect that changes the way that the patient dies, the effect is not beneficial on balance.").

mine whether and to what degree a particular outcome is beneficial. Some commentators suggest that using *net* benefit as a measure of futility inevitably involves potential conflicts of value and thus cannot appropriately be used as a measure of medical futility.⁶⁷

This argument is more easily understood if one considers the context in which a dispute about medical futility might arise. If the patient has clearly indicated that she does not want a particular treatment, then she will not receive it whether or not the doctor believes it to be futile.⁶⁸ A judgment that a treatment is medically futile is only important in those cases in which the patient (or surrogate) either wants the treatment or has not expressed a view about the treatment. In such cases, the issue will then be whether the treatment may permissibly be withheld without the patient's permission.⁶⁹

Commentators who criticize the net-benefit definition claim that if there is a dispute about whether a treatment will provide a net benefit (i.e., the doctor and the patient disagree about how to weigh the costs and benefits of different possible outcomes), the issue is then not one of medical futility but instead of what to do when doctor and patient disagree about the relative worths of particular options.⁷⁰ They argue that in such cases either a hybrid approach should be used or the patient's values should triumph.⁷¹

Yet, this argument proves too much. Not only do analyses of net benefit invariably involve claims and potential conflicts about the values to be assigned to different outcomes, but even analyses of whether a treatment has any benefit at all invariably involve at least potential conflicts about value. If a treatment has any effect at all, that effect might be a benefit according to some value system. Thus, suppose that one had a fatal illness, a symptom of which was diminished sensi-

67. See, e.g., *id.* at 15 ("It is . . . when a patient or surrogate and the clinician disagree over the benefit that the patient will receive from an intervention, that is most interesting morally and that cannot properly be labelled medically futile." (emphasis omitted)).

68. Cf. Mark Strasser, *Assisted Suicide and the Competent Terminally Ill: On Ordinary Treatments and Extraordinary Policies*, 74 OR. L. REV. 539, 568-69 (1995) ("Patients clearly have the right to reject their physicians', or even the reasonable person's analyses about what constitutes the best course of treatment.").

69. See Steven Miles, *Futility and Medical Professionalism*, 25 SETON HALL L. REV. 873, 873 (1995) (explaining that the medical-futility debate is "about the medical prerogative to conclude that a treatment is so unlikely to be beneficial or its benefits are such a stark departure from the normative ends of healing, palliating, or rehabilitating medicine that a physician is not obliged to offer or prescribe the treatment").

70. See John D. Lantos et al., *The Illusion of Futility in Clinical Practice*, AM. J. MED., July 1989, at 81, 83 (discussing futility decisions when patients and doctors disagree about treatment options).

71. See *infra* notes 79-86 and accompanying text (discussing futility in terms of patient goals); *infra* notes 135-141 and accompanying text (discussing a hybrid approach).

tivity to pain. A treatment whose only effect was to increase the ability to feel pain might be viewed as beneficial—perhaps as a way to help one atone for one's sins—even if one was not able to understand or appreciate that one's increased pain was serving that end. A treatment whose only effect would be to extend one's nonconscious life might also be viewed as beneficial—perhaps out of a belief in the intrinsic value of life—even if the benefitted patient could never know that such a benefit had been conferred. If futility should not be defined in terms of treatments that produce no *net* benefit, because such a criterion involves a potentially irresolvable conflict of values, then neither should futility be defined in terms of treatment that produces no benefit at all, because, as with net-benefit analyses, those judgments might involve irresolvable conflicts of value.⁷²

Many deny that continuation of biological existence itself is necessarily a benefit, although there is disagreement about why that is so.⁷³ Some courts have suggested that such prolongations are not beneficial in those cases in which the patient will never have “a normal, functioning, integrated existence.”⁷⁴ Yet, even if treatment which merely prolongs biological existence is futile, that will not be simply because such a state does not involve a normal, functioning, integrated existence. Indeed, using this criterion would raise a whole host of difficulties, because, if for no other reason, it is by no means clear how “normal functioning” should be defined. A criterion for futility must be developed that neither requires normal functioning nor limits medical futility to treatments that will have no effect whatsoever.

The claim here is not that medical futility *could* not be defined in terms of treatments that produce no effect, but that such a definition is counterproductive and does not account for the common understanding of the term. If futility is defined in terms of the inability of a treatment to produce *any* effect, then the only treatments that will be

72. *But see supra* notes 52-56 and accompanying text (suggesting that the no-effect criterion is underinclusive).

73. *See infra* notes 197-202 and accompanying text (discussing different reasons why treatments may be futile if they prolong the lives of persons who have experienced upper-brain deaths).

74. *In re Dinnerstein*, 380 N.E.2d 134, 138 (Mass. App. Ct. 1978); *accord* *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 345-46 (1990) (Stevens, J., dissenting) (“Life, particularly human life, is not commonly thought of as a merely physiological condition or function.”); *In re Cicero*, 421 N.Y.S.2d 965, 967 (Sup. Ct. 1979) (distinguishing the case before it from one in which “the court is asked to preserve an existence which cannot be a life”).

precluded on futility grounds would be those that arguably should not even have been "treatment candidates" in the first place.

In *United States v. Rutherford*,⁷⁵ the Supreme Court suggested that a drug is effective if it produces "prolonged life, improved physical condition, or reduced pain."⁷⁶ If futility is to be defined in terms of a treatment producing no effect, however, the minimal standards suggested by *Rutherford* for the efficacy of the treatment would still be too robust to adopt. Indeed, on the no-effect view, a treatment that would aggravate the condition would not be futile, because it would have an effect on the patient.⁷⁷

Presumably, very few—if any—commentators would be tempted to say that a treatment whose only effect is to produce pain would be nonfutile.⁷⁸ Yet, the difficulty posed by deciding whether medical futility should be defined in terms of a treatment producing no benefit or no net benefit has induced commentators to consider other options, one of which involves incorporating the patient's own goals into an analysis of what the concept of futility means.

C. Patient Goals

Some commentators suggest that futility should be defined in terms of the efficacy of a treatment in meeting the *patient's* goals.⁷⁹ At first glance, this proposal seems plausible: If the only effect a treatment will have is to promote the biological existence of the patient, and the patient does not want merely to have her biological existence extended, then providing that treatment would be futile.

Commentators view the futility-as-nonproduction-of-patient's-goals definition as rather narrow, and they imply that the only ques-

75. 442 U.S. 544 (1979).

76. *Id.* at 555.

77. This is to be distinguished from assistance-in-dying, which is not viewed as "treating" a disease but, instead, as a separate issue that implicates autonomy and privacy considerations. See Strasser, *supra* note 68, at 539 (discussing constitutional aspects of assisted suicide).

78. But see Stern, *supra* note 50, at 1008 (suggesting that patients should be allowed to "choose to endure possibly painful, futile treatments").

79. See, e.g., Daar, *supra* note 48, at 1255 ("[M]edical futility may be better defined by discerning the likelihood that a particular treatment will produce the benefit sought by the patient. If treatment will not produce a benefit sought by the patient, it can be considered futile."); Veatch & Spicer, *supra* note 51, at 35 ("[P]hysicians have an expertise in deciding whether an intervention will have an effect. They should be permitted to refuse to provide a service that they can claim, based on reasonable medical knowledge, will not have the effect that the patient desires.").

tion is whether futility should be defined more broadly.⁸⁰ Yet, commentators' claims notwithstanding, such a criterion is both too narrow and too broad. Suppose, for example, that a particular treatment will not cure the patient as quickly as she would like, although she understands that it will indeed effect a cure. The treatment would be futile, because it could not achieve her goals. Yet, it hardly seems appropriate to call a treatment futile when that treatment would in fact cure the person and return her to "normal functioning,"⁸¹ even if it works less quickly than she would like.

Part of the robustness of the notion of patient autonomy involves the patient's right to reject undesired *effective* treatment.⁸² Indeed, if a patient does not believe that life would be worth living even with certain medical benefits, that patient has the right to refuse any treatment that would provide those benefits, even if those benefits were the results of the most medically beneficial treatment available to the patient.⁸³ However, equating futile treatment with treatment that does not promote the patient's goals is counterproductive for at least two different reasons: (1) it would have the counterintuitive result that the most beneficial treatment could, conceivably, be termed medically futile; and (2) it would render the concept of medical futility virtually meaningless, because the only time that it would preclude a treatment that would not be precluded by a patient's exercise of au-

80. See, e.g., Dale L. Moore, *Challenging Parental Decisions to Overtreat Children*, 5 HEALTH MATRIX 311, 315 (1995) ("Certainly a treatment that will not work, because it 'will not produce the effect being envisioned,' is futile by even the most restrictive definition." (footnote omitted)).

81. But see Stuart J. Youngner, *Who Defines Futility?*, 260 JAMA 2094, 2094 (1988) ("An intervention that kept a patient alive for six months might well be judged futile because it did not achieve an important goal of the patient—[e.g.], being able to walk and take care of his or her own personal hygiene.").

A separate question is whether a competent adult should be allowed to refuse that treatment and instead opt for a different treatment that would provide a quicker cure with more severe side effects. Reliance on patient autonomy would not, of itself, lead one to conclude that the rejected treatment would therefore be futile.

82. See Strasser, *supra* note 68, at 568 ("Where a clear conflict arises between a person's informed, autonomous decision and the 'best' result for that person, the former must be respected.").

83. See *Bouvia v. Superior Court* (Glenchur), 225 Cal. Rptr. 297, 300 (Ct. App. 1986) (holding that a patient has a right to refuse treatment, even when that treatment might prolong her life); Strasser, *supra* note 68, at 568-69 ("Patients clearly have the right to reject their physicians', or even the reasonable person's analyses about what constitutes the best course of treatment.").

tonomy would be when the treatment was desired by the patient, *even though the treatment would not promote the patient's goals*.⁸⁴

Presumably, there would be relatively few cases in which a patient would want a treatment even though it would not promote her goals. Indeed, if a patient were to insist upon receiving a particular treatment, even after having been informed that it would not promote her stated goals, one might infer that the patient had other unstated goals that she believed would be promoted by receiving the treatment. Thus, the not-meeting-the-patient's-goals notion of futility would seem to do very little work indeed, because very few—if any—of the treatments that would be rejected on futility grounds would not also be rejected on autonomy grounds.

Suppose that treatment *A* would promote a patient's goals, albeit to a lesser extent than would alternative treatment *B*. It would be unclear how to classify treatment *A*. Arguably, it should be considered futile, because it does not meet the patient's goals in the most effective way possible, especially if efficacy is itself a goal of the patient; yet, on the other hand, treatment *A* should not be considered futile, because it would promote the patient's goals to some extent, even if not as effectively as treatment *B* would.

A different and more subtle concern involves the misunderstandings that might result from linking futility to patients' desires and goals. Suppose that medical futility is definitionally linked to those treatments a patient might refuse. Suppose further that medical futility is *also* definitionally linked to those treatments that have proven ineffective. It is foreseeable that individuals might misconstrue the relevant definitions and decide that patients only have a right to refuse futile, that is, ineffective treatments. Even were this confusion not to be manifested in court decisions but, instead, "merely" in actual medical cases not challenged in court, patients might still be forced to undergo unwanted treatment and needless suffering because of such a misunderstanding.

A separate point involves what patients do when they seek advice from their doctors. A patient's decision about whether to have a given treatment might itself depend upon whether the doctor believes that the treatment is futile. When asking the doctor whether a treatment would be futile, the patient might not merely be asking whether the treatment would in fact help the patient attain her goals, but instead,

84. See Daar, *supra* note 48, at 1257 ("[T]he AMA concludes that treatment would be considered futile if it could not be expected to achieve the goals expressed by the informed patient, and therefore could be withheld even if requested by the patient.").

the patient might also be asking about the likely benefits and costs of the treatment.

A doctor who is asked whether a particular treatment is futile *might* refuse to make such a judgment until the patient has engaged in extensive value and goal clarification, because the doctor could then make a more accurate judgment about whether, in fact, the treatment would promote the patient's goals.⁸⁵ Yet, it would be both surprising and counterproductive to *require* such a clarification before a futility judgment could be made, because the patient (or surrogate) might not have the interest, time, energy, training, or ability to do the required analysis. Futility judgments are not simply reducible to analyses of whether treatment will help the patient attain her actual or presumed goals.

Defining futility in terms of patient goals gives rise to other counterintuitive implications. Consider two patients with identical prognoses and pain tolerances. On the patient-indexed notion of futility, a given treatment might be medically futile for one and not for the other because of a difference in the two patients' *values*. While the common understanding of futility can easily account for a treatment being futile for one patient and not for another—because the prognoses of the two patients differ—that understanding cannot as readily account for the same treatment being futile for one patient and not for another even though the patients have the same diseases and prognoses.⁸⁶

At least in part because of some of the counterintuitive implications of using a patient-indexed definition of futility, some people seek a more objective definition of futility.⁸⁷ One could say, for example, that “‘medically futile means that cardiac resuscitation would be

85. The American Medical Association's Council on Ethical and Judicial Affairs noted: Patients, therefore, should be encouraged to discuss with their physicians the expected benefits and objectives of medical treatment and to engage in an ongoing dialogue regarding the potential for achieving these goals. Once the objectives of the patient have been clearly expressed, the physician can determine and convey to the patient whether CPR or other medical treatments are likely to be effective in helping to achieve those goals.

Council on Ethical & Judicial Affairs, *supra* note 48, at 1870.

86. *But cf.* Kathleen M. Boozang, *Death Wish: Resuscitating Self-Determination for the Critically Ill*, 35 ARIZ. L. REV. 23, 63 (1993) (“Because the physician does not base the futility determination exclusively on objective medical criteria, the law should enable the patient to retain ultimate authority to decide whether futile treatment should be withheld or withdrawn.”); Philip J. Boyle, *Religious Reasoning in Health Care Resource Management: The Case of Baby K*, 25 SETON HALL L. REV. 949, 955 (1995) (rejecting the assumption that “medical judgments are objective, value-free, and preferred over religious, value-laden reasons”).

87. *But see* David M. Smolin, *Praying for Baby Rena: Religious Liberty, Medical Futility, and Miracles*, 25 SETON HALL L. REV. 960, 971 (1995) (stating that the broader “sense of medical

unsuccessful in restoring cardiac and respiratory function or that the patient will experience repeated arrests in a short period of time before death occurs.”⁸⁸

Defining futility in terms of the success of cardiac resuscitation might seem overly restrictive, both because it is limited to one particular kind of treatment, and because it would mean that an individual who had been resuscitated only to be in a coma for the rest of her life would not have received futile treatment.⁸⁹ Of course, in the latter example, it presumably would not have been clear that resuscitation would only result in a lifelong coma. There might have been an eighty-percent chance that the resuscitation would be successful in extending life and only a twenty-percent chance that a successful resuscitation would result in permanent coma. Resuscitation would have been offered in the hope that the patient's conscious life might thereby be extended.

Whenever decisions are being made regarding the futility of a particular procedure, the probabilities of particular outcomes must be considered.⁹⁰ Where there is no chance (a zero-percent probability) that a particular treatment will effect a change, then of course the treatment is futile.⁹¹ Suppose, however, that a particular treatment is effective one percent of the time. This treatment is not futile in the same sense that using antibiotics for a virus is futile,⁹² because there is

‘futility’ arguably implicates ethical and religious questions about both the purposes of human life and about death and dying”).

88. *In re Finn*, 625 N.Y.S.2d 809, 812 (Sup. Ct.) (quoting N.Y. PUB. HEALTH LAW § 2961(12) (McKinney 1993)), *modified sub nom.* *Finn v. Leonard C.*, 634 N.Y.S.2d 262 (App. Div. 1995).

89. *Cf.* GA. CODE ANN. § 31-39-2(4)(B) (1996) (“‘Candidate for nonresuscitation’ means a patient who, based on a determination to a reasonable degree of medical certainty by an attending physician with the concurrence of another physician: . . . Is in a noncognitive state with no reasonable possibility of regaining cognitive functions.”); *Morgan v. Olds*, 417 N.W.2d 232, 234 (Iowa Ct. App. 1987) (“Resuscitation was again successful and Morgan survived; however, Morgan suffered brain damage due to a lack of oxygen to the brain and lapsed into a coma from which he never awoke.”).

90. *See* Smith, *supra* note 53, at 8-9 (“When the physician wishes to withhold treatment on the grounds of futility because the treatment is unlikely to produce a desired benefit, however, the physician must balance the . . . statistical probabilities of success or harm derived through experimentation and analysis of hospital data.”); *cf.* Veatch & Spicer, *supra* note 51, at 18 (“[W]hen a medical scientist makes the apparently scientific claim that a treatment will have no relevant effect, he or she is making a probabilistic prediction.”).

91. *See* George J. Annas, *The “Right to Die” in America: Sloganeering from Quinlan and Cruzan to Quill and Kevorkian*, 34 DUQ. L. REV. 875, 888 (1996) (discussing a case in which the doctors wrote “a DNR order because they believed it was impossible to resuscitate [the patient] anyway, i.e., it would be futile”).

92. *See* Levine, *supra* note 49, at 79 (“Characterizing a treatment as ‘useless’ based on the extremely low chance that a physiological effect will occur requires an opinion that this low probability is not worth pursuing, not a scientific determination that the physiological

some chance that the treatment will lead to a desirable outcome. However, it is simply unclear whether a treatment that is effective one percent or even five percent of the time should be considered futile.⁹³

There is some probability of success at or below which treatments should be considered futile. Whether the appropriate threshold should be set at one percent or ten percent is a matter of dispute.⁹⁴ A complicating factor is that one threshold might be set to determine which treatments are medically futile and a different threshold might be set to determine which *nonfutile* treatments are nonetheless sufficiently unlikely to be successful to warrant not being offered.⁹⁵ While a treatment exceeding the former but not the latter threshold would still not be offered, the *reason* that it would not be offered would not involve futility but, for example, scarce resources.⁹⁶

The determination of the threshold probability of success below which a treatment would be considered futile cannot be made without at least implicitly considering which among a range of goals might appropriately be considered relevant. This is because the probability of reaching a relatively modest goal would usually be much higher than the probability of reaching a very ambitious goal. As suggested above, it would be inappropriate to use immediate cure as the goal when determining whether a treatment is futile.⁹⁷ Even if there is a zero-percent probability that a particular treatment would effect a cure immediately, that should not make the treatment futile.

effect sought is scientifically impossible.”); *see also supra* notes 49-56 and accompanying text (discussing the futility of, among other things, using antibiotics to treat a virus).

93. *See* Lantos et al., *supra* note 70, at 83 (“[T]he patient and the doctor must together determine whether the probability of attaining desired goals is so low that therapy may be deemed futile.”); Erich H. Loewy & Richard A. Carlson, *Futility and Its Wider Implications: A Concept in Need of Further Examination*, 153 ARCHIVES INTERNAL MED. 429, 430 (1993) (“But what about something that has a 0.05% chance of success; what about 0.1%, 2%, or 5%?”); Nealy, *supra* note 22, at 138 (“Whether or not a one-percent chance of success or even a five-percent chance of success is low enough to be characterized as futile treatment is highly debatable.”).

94. *See* Council on Ethical & Judicial Affairs, *supra* note 48, at 1870 (“[S]ome physicians describe a medical treatment as futile only if the possibility of success approaches 0%, whereas others associate futility with success rates as high as 13%.”).

95. *See infra* notes 203-206 and accompanying text (distinguishing between futility and rationing).

96. *See infra* note 206 and accompanying text (discussing how justifications for futility and rationing differ).

97. *See supra* text accompanying notes 80-86 (implying that it would be inappropriate to deem futile a treatment that would cure a patient, even though the treatment would not effectuate a cure as quickly as the patient would like).

D. Qualitative and Quantitative Judgments

When discussing the range of outcomes that might appropriately be the basis of a judgment that a given treatment is futile, commentators distinguish between two types of judgments: qualitative and quantitative judgments.⁹⁸ A qualitative judgment involves an analysis of the quality of life the individual may have if offered treatment.⁹⁹ A quantitative judgment, on the other hand, involves an analysis of the likelihood that a treatment will achieve a particular result (e.g., how often a treatment was effective in the last 100 cases in which it was used for a particular condition, or how long the individual will live even with treatment).¹⁰⁰

1. *Qualitative Judgments.*—Some commentators suggest that futility judgments must involve an analysis of what the patient's life will be like if she receives treatment.¹⁰¹ This analysis may involve focusing on whether the patient is expected to be conscious or able to enjoy life.¹⁰² Other commentators focus on whether further treatment will only produce increased suffering.¹⁰³ The important issue to be resolved is whether the attainable quality of life is itself worthy of pursuit.¹⁰⁴

98. See Shiner, *supra* note 42, at 827 ("One can consider two broad conceptions of futility: (1) care that produces no effect (physiological or quantitative futility), and (2) care that produces an effect, but offers no benefit (qualitative futility).").

99. See Daar, *supra* note 48, at 1254 (defining qualitative futility as "focusing on the nature of individual benefit").

100. *Id.* (defining quantitative futility as "focusing on the degree of overall success"); see also Morreim, *supra* note 25, at 886 (discussing the argument that treating anencephalic infants is futile because they will die soon no matter what is done); Schneiderman et al., *supra* note 50, at 951 (proposing that when physicians conclude "that in the last 100 cases, a medical treatment has been useless, they should regard that treatment as futile"); cf. Council on Ethical & Judicial Affairs, *supra* note 48, at 1870 ("The successful application of CPR also has been gauged by criteria that relate to the length of patient survival. Such criteria include, for example, survival for at least 24 hours following initial resuscitation, survival until discharge from the hospital, and survival for some other time frame.").

101. See, e.g., Rhoden, *supra* note 32, at 1304 ("To adequately assess benefit, the nature of the life being preserved cannot be ignored.").

102. See Morreim, *supra* note 25, at 886 (discussing the argument that treating anencephalic infants "is futile because they will never be conscious or enjoy any form of human experience"); Rhoden, *supra* note 32, at 1317 ("The permanently unconscious infant is the clearest indication that 'vitalism,' the view that mere biological existence must be preserved at all costs, is untenable, especially since modern technology can prolong life indefinitely.").

103. See, e.g., Rhoden, *supra* note 32, at 1315 (suggesting that although treating an infection of a permanently unconscious infant is "virtually futile, such treatment itself is not painful" and therefore should be required).

104. See Nancy S. Jecker & Robert A. Pearlman, Commentary, *Medical Futility: Who Decides?*, 152 ARCHIVES INTERNAL MED. 1140, 1141 (1992) (discussing "the position that at

The decision about whether a particular quality of life is worthy of pursuit might be approached in several different ways. One might make the decision in light of the patient's own values,¹⁰⁵ which in turn may implicate religious values.¹⁰⁶ This approach basically mirrors an autonomy approach—the judgment would reflect what the patient said or would have said had she been competent and able to manifest her desires.¹⁰⁷

A different way to analyze the quality-of-life considerations would be to examine the possible effects that the treatment will have on the person's own life *without considering how the patient would have valued those effects*.¹⁰⁸ Suppose, for example, that a particular treatment could at best prolong the patient's biological existence. The patient would be unable to appreciate the continued life, because she would never be restored to consciousness. This quality of life would seem sufficiently low to justify classifying the treatment as futile, *even if the patient had previously expressed the desire to receive such treatment*.¹⁰⁹

Commentators sometimes suggest that qualitative futility judgments involve whether the treatment will benefit the *person*,¹¹⁰ not

some point along a continuum the quality of life associated with an intervention becomes so poor that the decision to withhold or withdraw treatment no longer rests with the patient (or surrogate) . . . [but] becomes, instead, the physician's prerogative").

105. See *In re Visbeck*, 510 A.2d 125, 132 (N.J. Super. Ct. Ch. Div. 1986) ("Responsible people who believe that quality of life factors should be considered . . . are looking at the matter from the viewpoint of the patient herself."); *Developments in the Law—Medical Technology and the Law*, 103 HARV. L. REV. 1519, 1652 (1990) [hereinafter *Medical Technology and the Law*] ("Courts generally agree that if quality-of-life considerations have any influence at all, the appropriate scope should be defined by the value to the patient").

106. See Smolin, *supra* note 87, at 971 (discussing a "sense of medical 'futility' [that] arguably implicates ethical and religious questions about both the purposes of human life and about death and dying").

107. See generally Mark Strasser, *Incompetents and the Right to Die: In Search of Consistent Meaningful Standards*, 83 KY. L.J. 733 (1994-1995) (discussing autonomy issues in the light of incompetent patients).

108. Cf. Morreim, *supra* note 25, at 901 ("It is meaningless to speak of [Baby K's] 'opportunities' or of her 'participation' in society. Heroic medical care could extend her life, but being alive made no further difference in her own life.").

109. See Crossley, *supra* note 29, at 188 (describing a procedure that, although prolonging the patient's survival, "would not provide any benefits that she seems capable of appreciating").

110. See *id.* (discussing the view that the relevant question is "whether a proposed treatment offers any benefit to the patient as a whole person, not simply whether the treatment will produce discrete physiological effects"); Jecker & Pearlman, *supra* note 104, at 1141 ("[T]he house staff's judgment that treatment is futile may reflect their assessment that nutrition and hydration produces a *physiologic effect* without conferring a *medical benefit* to the patient."); cf. Annas, *supra* note 91, at 879 ("[Anencephalic infants] are in very bad shape, and there is nothing we can do to benefit them. We certainly have no obligation to treat them."); Dzielak, *supra* note 62, at 764 ("Treatment that cannot alter the irreversible nature of permanent unconsciousness or dependence on intensive medical care conse-

merely her organs,¹¹¹ and that "treatment that provides an effect to a portion of the body without providing a benefit to the person as a whole is futile."¹¹² They would suggest that extending the life of someone in a permanent vegetative state might benefit the person's kidneys, for example, but would not benefit the person herself.¹¹³

The view that treatment is futile if it benefits organs but not persons might be justified in a few different ways (e.g., by establishing that there is a societal consensus to that effect).¹¹⁴ Of course, as a general matter, societal consensus should not be the sole basis upon which the definition of futility should be based. Appropriate safeguards would have to be in place to prevent a societal consensus from establishing that an obviously nonfutile treatment was nonetheless futile;¹¹⁵ otherwise, individuals might be denied the protection that they are due under the Constitution.¹¹⁶ It would be important to make sure that the societal consensus about futility did not involve an attempt to discriminate invidiously against a disfavored group.¹¹⁷

Two points should be made with respect to the potential invidiousness of describing treatments as futile if they would merely prolong vegetative existence. First, in order to assert the futility of

quently cannot improve a patient's quality of life and therefore is futile."). *But see* Crossley, *supra* note 29, at 224 (criticizing commentators who "suggest that life-sustaining nutritional support is futile for persons in a persistent vegetative state, despite their potential to live for many years if provided with medical support" (footnote omitted)).

111. *See* Rhoden, *supra* note 32, at 1317 ("[W]e seek benefits to persons, not to isolated organs.").

112. Allen J. Bennett, *When Is Medical Treatment "Futile"?*, 9 ISSUES L. & MED. 35, 39 (1993) (describing the view that a "treatment that provides an effect to a portion of the body without providing a benefit to the person as a whole is futile").

113. *See* Rhoden, *supra* note 32, at 1320 ("[D]ialysis would have 'benefitted' Karen Ann Quinlan's kidneys but could not have helped Karen Ann.").

114. *See* Rebecca Dresser, *Missing Persons: Legal Perceptions of Incompetent Patients*, 46 RUTGERS L. REV. 609, 649 (1994) ("The quality-of-life judgment that unconscious life need not be sustained is eminently defensible. . . . [Society] substantially supports this quality-of-life judgment."); *Medical Technology and the Law*, *supra* note 105, at 1603 ("A morally legitimate approach to neonatal intensive care decisionmaking must involve some quality-of-life judgments. Such judgments must spring from a social consensus based on moral values and medical knowledge.").

115. *Cf. infra* notes 212-218 and accompanying text (discussing misperceptions of what it is like to live with a disability).

116. *Cf. Dred Scott v. Sandford*, 60 U.S. (19 How.) 393, 405-06 (1856) (denying citizenship and various constitutional protections to African Americans).

117. In *Cleburne v. Cleburne Living Center, Inc.*, 473 U.S. 432 (1985), the Court refused to characterize the mentally handicapped as a quasi-suspect class. *Id.* at 442-43. The Court, however, may have been using a heightened rational-basis test to strike the zoning law at issue. *See* Mark Strasser, *Unconstitutional? Don't Ask, If It Is, Don't Tell: On Deference, Rationality, and the Constitution*, 66 U. COLO. L. REV. 375, 430-31 (1995) (discussing the *Cleburne* rational-basis test).

treatment that merely prolongs permanent unconsciousness, one need not contend that the permanently unconscious are nonpersons. This is because the futility of such treatment would be due to the quality of life it would produce and not to the nonpersonhood of the potential recipient. Arguably, this futility classification does not involve an invidious distinction but rather a claim that the possible "benefit" would not meet the qualitative threshold below which treatment should be considered futile.

Second, suppose a claim were made that the permanently unconscious were not persons in a constitutional sense and thus did not have a right to treatment.¹¹⁸ Such a claim, even if accepted, would have fewer legal implications than might originally be supposed; for example, it would *not* imply that such individuals would be without legal protection. Just as the state may have compelling interests in protecting fetuses,¹¹⁹ even though they are not persons in a constitutional sense,¹²⁰ the state would presumably have important if not compelling interests in protecting the permanently unconscious, even if they were not protected by the Fourteenth Amendment. Thus, even if the permanently unconscious were classified as nonpersons, this would not imply, for example, that they could be used as a source for organs against their previously expressed wishes or their family's will.¹²¹

2. *Quantitative Judgments.*—Quantitative judgments involve analyses of the likelihood that a particular goal will be achieved or that life will in fact be extended.¹²² Some courts and commentators suggest that quantitative futility is the only appropriate measure of futility, and

118. Sometimes, anencephalic infants are described as nonpersons lacking treatment rights. See Jay A. Friedman, *Taking the Camel by the Nose: The Anencephalic as a Source for Pediatric Organ Transplants*, 90 COLUM. L. REV. 917, 957 (1990) ("Anencephalics, who lack the capacity or potential for even the most minimal level of cogitation and social interaction, clearly are [nonpersons]."); John A. Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213, 251 (1975) ("[T]he only group of defective newborns who would clearly qualify as nonpersons is anencephalics, who altogether lack a brain.").

119. See *Planned Parenthood v. Casey*, 505 U.S. 833, 860 (1992) (plurality opinion) ("[V]iability marks the earliest point at which the State's interest in fetal life is constitutionally adequate to justify a legislative ban on nontherapeutic abortions.").

120. See *Roe v. Wade*, 410 U.S. 113, 158 (1973) ("[T]he word 'person,' as used in the Fourteenth Amendment, does not include the unborn.").

121. Although other reasons might be proffered, some commentators suggest that because anencephalic infants are persons, their organs cannot be harvested. See, e.g., Annas, *supra* note 91, at 879.

122. See Crossley, *supra* note 29, at 188 (discussing the view of certain theorists that quantitative futility involves "the probability that any benefit will be achieved"); Morreim, *supra* note 25, at 886 ("Quantitatively, [treatment] is futile because an anencephalic like

that it is simply inappropriate to consider quality of life judgments in this context.¹²³ Yet, even if that were true, the relevant issues would not thereby be settled, because the question might then be whether the prolongation of vegetative existence really counts as an extension of "life." Justice Stevens has suggested that for patients "who have no consciousness and no chance of recovery, there is a serious question as to whether the mere persistence of their bodies is 'life' as that word is commonly understood, or as it is used in both the Constitution and the Declaration of Independence."¹²⁴

Even if one puts aside the concerns raised by Justice Stevens, and even if one uses quantity of life as the relevant criterion, there will still be the need to establish the relevant quantitative threshold (e.g., whether a few more minutes of life would suffice to make the treatment nonfutile, or whether, instead, the treatment must yield weeks or months of additional life). However, even a relatively robust quantitative futility standard—requiring, for example, treatment to extend life for weeks—might not be sufficiently robust to exclude treatment that most commentators would call futile: It has been reported that "individuals" who are completely brain dead may, nonetheless, be kept "alive" for weeks.¹²⁵

For some patients, further medical treatment will be futile both quantitatively and qualitatively, so it will not matter which criterion is employed to establish futility.¹²⁶ However, unless some qualitative measure of futility is used, others could be kept alive indefinitely

Baby K will die soon no matter what physicians do." (emphasis omitted)); Dzielak, *supra* note 62, at 754 ("Under a quantitative analysis, treatment is not futile if it prolongs life.").

123. See, e.g., *Cruzan by Cruzan v. Harmon*, 760 S.W.2d 408, 419 (Mo. 1988) (en banc) ("The state's concern with the sanctity of life rests on the principle that life is precious and worthy of preservation without regard to its quality."), *aff'd sub nom. Cruzan by Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261 (1990); see also *supra* notes 58-65 and accompanying text (discussing what treatment outcomes constitute benefits). However, some courts disagree:

If we require treatment decisions to be made without any reference to quality of life factors, we will be creating other kinds of risks of bad decision making. Worse than that, we will be guaranteeing that bad decisions will be made and that large numbers of people will be thoughtlessly and automatically compelled to continue lives of intolerable bleakness.

In re Visbeck, 510 A.2d 125, 133 (N.J. Super. Ct. Ch. Div. 1986).

124. *Cruzan by Cruzan*, 497 U.S. at 345 (Stevens, J., dissenting). But cf. Edward R. Grant, *Medical Futility: Legal and Ethical Aspects*, 20 L. MED. & HEALTH CARE 330, 331 (1992) ("There is another risk, not so frequently identified, that the language of futility could be misconstrued to imply that it is the futility (or utility) of the patient's life that is under consideration.").

125. See *infra* note 164 and accompanying text.

126. See, e.g., Morreim, *supra* note 25, at 886 (suggesting that treating anencephalic infants is futile both quantitatively and qualitatively).

(without their ever gaining consciousness), despite the absence of any brain functioning at all.¹²⁷ In part because some of these life extensions seem futile *even if desired*, some commentators offer definitions of futility that include both qualitative and quantitative components.¹²⁸ For example, some suggest that a futility determination should involve whether the individual will be able to leave the hospital.¹²⁹ This test involves both quantitative and qualitative elements, because the individual would not only have to survive for a certain period of time, but she would also have to have a quality of life that would allow her to live outside the hospital setting.

For a certain class of patients, it is unlikely that treatment would ever allow them to live outside of the hospital.¹³⁰ A separate question would be whether treating them would therefore be futile.¹³¹ Even if there is little hope that a patient will be able to leave the hospital after receiving treatment,¹³² there may be some hope that life could be extended for several days, thereby allowing the patient to say

127. See *infra* note 164 and accompanying text.

128. See, e.g., Crossley, *supra* note 29, at 188 (discussing a definition of futility that "involves both qualitative and quantitative components").

129. See *id.* at 188-89 (discussing the viewpoint that "if studies reveal that, among patients with metastatic cancer, none has survived to hospital discharge after receiving CPR, then resuscitating patients with metastatic cancer should be considered futile").

130. See Paul C. Sorum, *Limiting Cardiopulmonary Resuscitation*, 57 ALB. L. REV. 617, 621 (1994) (discussing a kind of "patient whose serious underlying disease puts him or her in a category in which survival after an arrest and resuscitation until discharge from the hospital would be unprecedented, or, as others would insist, a category in which survival is rare if not actually unprecedented" (footnote omitted)).

131. See *id.* at 622 (suggesting that it is "illegitimate for a physician to deny the option of CPR to his or her patient on the grounds that the patient is going to die soon anyway").

132. But see *id.* ("[W]hen a variety of studies of the outcomes of CPR are examined, no category of patients is without some survivors to discharge. It would be very difficult, if not impossible, therefore, to draw the line between those for whom CPR is futile and those for whom it is not." (footnote omitted)).

good-bye to loved ones.¹³³ It simply is impossible to determine whether such additional time would not be worth living.¹³⁴

E. Hybrid Futility Judgments

Some commentators suggest that futility judgments should be based upon a hybrid approach incorporating both physician and patient perspectives.¹³⁵ Under this approach, medical personnel would not undervalue the benefits that might be accrued by treatment and conclude that a particular treatment would be futile when the patient would have concluded otherwise.¹³⁶

Consider the claim that treatment is futile because it will not allow the patient to leave the hospital.¹³⁷ Arguably, this example illustrates the weakness of defining futility objectively: For some patients, such a treatment would be futile, but for those patients who want to see a relative one last time, it would not be futile.¹³⁸ Yet, appearances

133. One commentator explains:

Many of the studies to which Murphy refers measure futility of CPR by whether or not the resuscitated patients lived to leave the hospital. Using this standard, CPR was futile if the patient lived a week, but died before discharge. . . . Living for five more days might give some patients the opportunity to say good-byes, to wait for the arrival of a loved one from another city, or to live to see the birth of a grandchild.

Youngner, *supra* note 81, at 2094-95 (commenting on Donald J. Murphy, *Do-Not-Resuscitate Orders: Time for Reappraisal in Long-term—Care Institutions*, 260 JAMA 2098 (1988)); accord Levine, *supra* note 49, at 78 ("While postponing death for one week may seem worthless to some, others may find it a noble cause. For example, consider the elderly patient nearing death who wants to see the grandchild she was never able to meet." (footnote omitted)); Nealy, *supra* note 22, at 138 ("Even when a course of treatment is deemed futile, living for five more days might give some patients the opportunity to say good-byes, to wait for a loved one to arrive from another city, or simply to come to terms with the grief of losing a loved one.").

134. Cf. Sorum, *supra* note 130, at 623 ("[P]atients frequently adjust to and find some benefit in even painful and restricted modes of existence.").

135. Cf. Daar, *supra* note 48, at 1254 ("Any single definition of medical futility, be it qualitative (focusing on the nature of individual benefit) or quantitative (focusing on the degree of overall success), can be criticized for failing to include some component of individual patient goals."); Lantos et al., *supra* note 70, at 84 ("Futility determinations, like all treatment choices, must include both clinical judgments about the chance of success of a therapy and an explicit consideration of the patient's goals for therapy."); Levine, *supra* note 49, at 82 ("Based on this contemporary notion of shared decisionmaking, both the physician's recommendations and the patient's ultimate decision on a proposed course of treatment are essential to any medical decision.").

136. See *infra* notes 212-218 and accompanying text (discussing whether individual doctors or society as a whole should define what constitutes futile treatment).

137. Cf. Sorum, *supra* note 130, at 622 ("The real debate about futility thus narrows down to whether CPR can be deemed futile . . . where survival to hospital discharge would be unprecedented or at least rare, as in fact the American Heart Association and the other major proponents of the futility argument have claimed." (footnote omitted)).

138. One commentator notes:

to the contrary notwithstanding, this example fails to establish that futility should not be defined objectively; rather, this example suggests that there is a danger of conflating two different issues: (1) whether the objective standard has been set at the appropriate level, and (2) whether futility must involve both objective and subjective standards.

Merely because a patient does not want to receive treatment does not make that treatment futile. In the example above, the treatment that would result in four additional days of relatively pain-free consciousness would presumably not be medically futile for *either* patient. This would hold true even if one patient would opt for the procedure to see relatives for one last time, but the other would not. Indeed, by deeming treatment for the latter patient futile merely because it was not desired, one risks undermining the notion that patients can refuse nonfutile treatment.¹³⁹

The example above suggests that the objective futility threshold must be set low enough to allow an individual who is receiving treatment to see a loved one for one last time, and also that medical treatment should not be deemed futile merely because the patient does not want additional treatment.¹⁴⁰ While it will not be easy to set the correct futility threshold,¹⁴¹ this neither implies that no reasonable consensus can be reached nor that futility must include a patient-centered component.

Some commentators suggest that whenever a patient's values require that treatment be continued, those values should be respected.¹⁴² Yet, this attitude is not reflected in other areas of the

[W]hile one patient may refuse CPR because she is informed of the low likelihood that she will ever leave the hospital, another patient may request that he be resuscitated just for the chance that he might be alive to see the arrival of a close relative, or his next birthday, or another sunrise.

Daar, *supra* note 48, at 1254.

139. See *supra* notes 83-84 and accompanying text (discussing patient autonomy and the danger of equating futile treatment with treatment that does not promote the patient's goals).

140. See Jecker & Pearlman, *supra* note 104, at 1142 ("[T]here are treatments where a broad community consensus holds that the quality of outcome associated with treatment falls well below a threshold considered minimal.").

141. Another commentator notes:

What would constitute a reasonable minimum level of benefit, like many other legal standards, is not easily reduced to a precise formula. Courts will have to rely to some extent on physician discretion, but it is also important that they set the threshold low enough to ensure that it provides meaningful protection for persons with disabilities.

Orentlicher, *supra* note 40, at 72.

142. Cf. Stern, *supra* note 50, at 1007 ("And if a patient is religiously commanded to 'choose life,' . . . then the state ought to honor that choice.").

law. For example, doctors have been *sanctioned* for treating individuals in ways that not only were *not* harmful, but that actually afforded patients relief unavailable from other treatments.¹⁴³ Were the patients' desires and values dispositive, doctors would not be *punished* for treating patients in ways that the patients themselves desired and believed beneficial.

Consider cases in which individuals seek to force insurance companies to pay for treatments that might have provided those individuals with their best hopes for survival.¹⁴⁴ Treatments that are not futile may nonetheless be *denied* because there is a lack of consensus about their efficacy.¹⁴⁵ Thus, an experimental therapy may be denied coverage,¹⁴⁶ even if there is substantial support for that treatment's effectiveness.¹⁴⁷ The denial of coverage may mean that the patient who cannot afford the cost of the treatment simply will be unable to receive that treatment.¹⁴⁸ The patients who seek such therapy are not

143. See *In re Guess*, 393 S.E.2d 833, 835 (N.C. 1990) (holding that a physician could be sanctioned even though "[t]here was no evidence that Guess' homeopathic treatment had ever harmed a patient, and there was anecdotal evidence that Guess' homeopathic remedies had provided relief to several patients who were apparently unable to obtain relief through allopathic medicine").

144. See, e.g., *Goepel v. Mail Handlers Benefit Plan*, Civ. A. No. 93-3711 (JEI), 1993 WL 384498, at *1 (D.N.J. Sept. 24, 1993) (acknowledging that "[t]here is a growing list of medical treatments and procedures . . . many of which have limited success rates, but many of which might be viewed as the only hope of survival by a desperately ill patient," but holding that the plaintiff was not entitled to insurance coverage for the treatment requested even though this treatment could be characterized as possibly life-saving), *vacated sub nom.* *Goepel v. National Postal Mail Handlers Union*, Div. of LIUNA, 36 F.3d 306 (3d Cir. 1994).

145. Consider the holding of one court:

[I]t is clear to the court that there is a lack of consensus within the medical profession regarding the appropriateness of using HDC-ABMT [high-dose chemotherapy with autologous bone marrow transplant] in the treatment of breast cancer at this time. The court finds, however, that based on the evidence before [the Office of Personnel Management], the agency's decision to exclude that treatment from coverage is rational.

Reger v. Espy, 836 F. Supp. 869, 872 (N.D. Ga. 1993).

146. See *Holder v. Prudential Ins. Co. of Am.*, 951 F.2d 89, 90 (5th Cir. 1992) (holding that an insurance company could partially deny "coverage based on the policy exclusion for experimental treatment").

147. See *Bechtold v. Physicians Health Plan*, 19 F.3d 322, 326 (7th Cir. 1994) (upholding the denial of coverage for treatment recommended by an oncologist); *Harris v. Mutual of Omaha Cos.*, 992 F.2d 706, 710 (7th Cir. 1993) (upholding the denial of coverage, notwithstanding the recommendation of a group of doctors referred to collectively as the "dream team" of oncology, whose views were widely relied upon in the field).

148. See *Barnett v. Kaiser Found. Health Plan, Inc.*, 32 F.3d 413, 415 (9th Cir. 1994) ("Both medical centers [UCLA and California Pacific], however, required that Barnett gain certification from his insurance provider, or that Barnett pay \$100,000 up front."); *Nesseim v. Mail Handlers Benefit Plan*, 995 F.2d 804, 805 (8th Cir. 1993) ("[T]he hospital

asking to receive painful, futile treatments,¹⁴⁹ but instead to receive treatments that may prolong their lives.¹⁵⁰ Indeed, today's experimental treatment might be tomorrow's highly recommended treatment;¹⁵¹ therefore, denial of treatment based on a lack of coverage might result in individuals being denied years of conscious life because they cannot pay the costs of treatment.

To some extent, insurance disputes are simply a matter of contract law.¹⁵² Ambiguous contracts may be construed to benefit the insured,¹⁵³ although there is a trend to uphold clearly written exclusions.¹⁵⁴ For purposes here, however, the issue is neither how to interpret particular clauses¹⁵⁵ nor whether insurance companies are blameworthy for denying treatment,¹⁵⁶ but that insurance contracts

required that the Nesseims make an advance payment of \$160,000 or obtain precertification of coverage from the Plan.”).

149. *But cf.* Stern, *supra* note 50, at 1008 (suggesting that patients should be allowed to “choose to endure possibly painful, futile treatments”).

150. *See* Morreim, *supra* note 25, at 909 (suggesting that if anencephalic infants and people in persistent vegetative states deserve treatment, then “we can hardly deny at least that level of care to people who are conscious and suffering—for instance, women with advanced breast cancer, whose only hope is an unproven but promising bone marrow transplant”).

151. *See* Loewy & Carlson, *supra* note 93, at 431 (“Therapy may be useless (‘futile’) today and very successful (and the norm) tomorrow.”).

152. *See* Mire v. Blue Cross/Blue Shield, 43 F.3d 567, 568 (11th Cir. 1994) (per curiam) (“We conclude that the plain meaning of the exclusion eliminates coverage for this suggested treatment for appellant’s non-germ cell ovarian cancer.”); *Fuja v. Benefit Trust Life Ins. Co.*, 18 F.3d 1405, 1410 (7th Cir. 1994) (“This clause in the contract clearly excludes coverage for treatment that is of uncertain medical efficacy and subject to ongoing, recognized and accepted medical research procedures.”); *Frendreis v. Blue Cross Blue Shield*, 873 F. Supp. 1153, 1160 (N.D. Ill. 1995) (mem.) (“The Frendreis/BCBSM policy is ambiguous and this Court therefore construes that ambiguity in favor of the insured and orders Defendant to supply coverage for the proposed PSCT [peripheral stem cell recovery] treatments.”).

153. *Cf. Frendreis*, 873 F. Supp. at 1160 (“[T]his Court therefore construes that ambiguity in favor of the insured . . .”).

154. *See* Daar, *supra* note 58, at 237 (discussing “a growing consensus among trial and appellate courts that insurance companies may legitimately refuse to pay for HDCT-ABMT [high-dose chemotherapy with autologous bone marrow transplant] if their written materials clearly and unambiguously exclude the treatment from coverage”).

155. *See, e.g.,* Dahl-Eimers v. Mutual of Omaha Life Ins. Co., 986 F.2d 1379, 1382 (11th Cir. 1993) (“Mutual of Omaha’s interpretation excludes coverage, but other reasonable interpretations may result in coverage.”).

156. It is not claimed here, however, that insurance companies are entirely blameless. *See, e.g.,* Katy Chi-Wen Li, *The Private Insurance Industry’s Tactics Against Suspected Homosexuals: Redlining Based on Occupation, Residence and Marital Status*, 22 AM. J.L. & MED. 477, 495-96 (1996) (describing insurance companies that redline based on presumed sexual orientation, which, in turn, is to be an indicator for the likelihood of contracting the HIV virus, despite the fact that the industry has not taken similar steps to screen out people with an increased chance of getting other, more costly diseases).

may well be based on the economics of treatment¹⁵⁷ or on other societal factors.¹⁵⁸ Given that patients are sometimes denied desired treatments that would offer some chance of extended conscious life, it is amazing that some commentators suggest that patient autonomy is being abridged if patients are not able to define for themselves what constitutes futile treatment.¹⁵⁹ It is also amazing that some commentators seem not to appreciate some of the other counterintuitive implications of the position that patients themselves must be allowed to define medical futility.¹⁶⁰

F. Death

Brain death is defined as the death of the entire brain, including the brain stem.¹⁶¹ An individual who is diagnosed as brain dead in accord with accepted medical standards may be declared legally dead.¹⁶²

157. See *Goepel v. Mail Handlers Benefit Plan*, Civ. A. No. 93-3711 (JEI), 1993 WL 384498, at *1 (D.N.J. Sept. 24, 1993) (referring to insurers who "attempt to avoid either insolvency or soaring premiums by excluding expensive or innovative health care procedures"), *vacated sub nom.* *Goepel v. National Post Mail Handlers Union*, Div. of LIUNA, 36 F.3d 306 (3d Cir. 1994).

158. *Barnett v. Kaiser Found. Health Plan, Inc.*, 32 F.3d 413, 417 (9th Cir. 1994) (upholding the permissibility of considering which patients have the best chances of survival when considering who will receive transplants of relatively scarce organs).

159. See Daar, *supra* note 48, at 1254 ("Any single definition of medical futility, be it qualitative (focusing on the nature of individual benefit) or quantitative (focusing on the degree of overall success), can be criticized for failing to include some component of individual patient goals."); *infra* note 224.

160. See *infra* notes 161-171 and accompanying text (demonstrating that, on this view, some brain-dead individuals might not be futile to treat whereas other individuals, with identical conditions and prognoses, would not only be futile to "treat" but would be legally dead).

161. See Strasser, *supra* note 107, at 788-94 (discussing the definition of death).

162. Several states have codified this rule:

In the case when respiratory and cardiac function are maintained by artificial means, a person is considered medically and legally dead if, in the opinion of a medical doctor licensed in Alabama, based on usual and customary standards of medical practice in the community for the determination by objective neurological testing of total and irreversible cessation of brain function, there is total and irreversible cessation of brain function. Death may be pronounced in this circumstance before artificial means of maintaining respiratory and cardiac function are terminated.

ALA. CODE § 22-31-1(b) (1990).

An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions in the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.

CAL. HEALTH & SAFETY CODE § 7180(a) (West Supp. 1997).

For legal and medical purposes, where respiratory and circulatory functions are maintained by artificial means of support so as to preclude a determination that

Consider an individual who is declared brain dead but whose parents nonetheless insist that she be "treated."¹⁶³ If the parents are obeyed, treatment may have to be offered for several weeks, because modern technology can sustain cardiopulmonary functions for a substantial period even after total brain death has occurred.¹⁶⁴ If any treatment is to be classified as futile, treating a dead person would seem to deserve that designation.

these functions have ceased, the occurrence of death may be determined where there is the irreversible cessation of the functioning of the entire brain, including the brain stem.

FLA. STAT. ANN. § 382.009(1) (West 1993).

- (1) An individual who has sustained either of the following is dead:
 - (a) Irreversible cessation of circulatory and respiratory functions.
 - (b) Irreversible cessation of all functions of the entire brain, including the brain stem.
- (2) A determination of death shall be made in accordance with accepted medical standards.

MICH. COMP. LAWS ANN. § 333.1033 (West 1992).

An individual who has sustained either irreversible cessation of circulatory and respiratory functions or irreversible cessation of all functions of the entire brain, including the brainstem, is dead. A determination of death must be made in accordance with accepted medical standards.

MONT. CODE ANN. § 50-22-101 (1995).

The determination that a person is dead shall be made by a physician licensed to practice medicine applying ordinary and accepted standards of medical practice. Brain death, defined as irreversible cessation of total brain function, may be used as a sole basis for the determination that a person has died, particularly when brain death occurs in the presence of artificially maintained respiratory and circulatory functions.

N.C. GEN. STAT. § 90-323 (1993).

An individual is dead if he has sustained either irreversible cessation of circulatory and respiratory functions or irreversible cessation of all functions of the brain, including the brain stem, as determined in accordance with accepted medical standards. If the respiratory and circulatory functions of a person are being artificially sustained, under accepted medical standards a determination that death has occurred is made by a physician by observing and conducting a test to determine that the irreversible cessation of all functions of the brain has occurred.

OHIO REV. CODE ANN. § 2108.30 (Anderson 1994).

163. See Daar, *supra* note 58, at 228 (discussing a case in which the daughter was declared dead but the parents insisted on further treatment).

164. See Friedman, *supra* note 118, at 965 ("[C]ardiopulmonary functions have been reported to survive for as long as sixty-eight days after complete loss of brain functions."). Individuals who have suffered upper-brain death may nonetheless survive indefinitely:

[T]wo neurologists . . . agreed that within a reasonable degree of medical certainty, Fiori's condition would not improve and he would remain in a PVS as he had done for the last seventeen years. They also stated that existing medical technology could continue to support Fiori's life functions so that his life span could extend for another ten to twenty years.

In re Fiori, 673 A.2d 905, 909 (Pa. 1996).

Arguably, in the example above, the parents' treatment demand could be rejected because the patient is no longer alive.¹⁶⁵ Even if each member of the family belongs to a particular religious group that rejects brain death as an appropriate criterion for death,¹⁶⁶ it will not matter unless there is a legal exception for individuals having such beliefs. After all, the patient is dead according to acceptable medical criteria and thus should not be treated.¹⁶⁷

Suppose, however, that this family lives in a jurisdiction where an exception has been made such that individuals whose religious beliefs preclude using brain death as the definition of death will not be declared dead according to that criterion.¹⁶⁸ Given the exception, treatment for this patient could not be ruled out on the ground that the patient was legally dead. Further treatment would maintain the "individual's" respiratory and cardiac functions and thus could not be ruled out on a purely quantitative notion of futility.¹⁶⁹ Assuming that this individual had previously expressed a desire to be treated under these circumstances, and assuming that the patient-centered notion of futility should control, treatment would not be futile for this patient.¹⁷⁰

To make matters more surprising, suppose that there is another individual identical to the first patient in all respects, except that this latter patient had not rejected brain death as a criterion of death.

165. The hospital did not take this position, however. See Daar, *supra* note 58, at 228.

166. See Philippe Ducor, *The Legal Status of Human Materials*, 44 *DRAKE L. REV.* 195, 213-14 (1996) ("Some deeply religious communities, particularly the Japanese and Jewish orthodox communities, have refused the brain-death criterion." (footnotes omitted)); Charlotte K. Goldberg, *Choosing Life After Death: Respecting Religious Beliefs and Moral Convictions in Near Death Decisions*, 39 *SYRACUSE L. REV.* 1197, 1214-15 (1988) ("[A]ccording to some Orthodox Jewish legal scholars 'brain death and irreversible coma are not acceptable definitions of death' Similarly, other cultures such as Native American and some Japanese do not recognize brain death." (footnotes omitted) (ellipsis in original)).

167. Cf. *In re Welfare of Bowman*, 617 P.2d 731, 732 (Wash. 1980) (en banc) ("We hold that it is for law to define the standard of death, that the brain death standard should be adopted, and that it is for the medical profession to determine the applicable criteria—in accordance with accepted medical standards—for deciding whether brain death is present.").

168. See N.J. STAT. ANN. § 26:6A-5 (West 1996) (authorizing an exemption from the use of brain-death criterion to establish death for those individuals for whom such a determination would violate their personal religious beliefs); see also Goldberg, *supra* note 166, at 1254 ("In New York, reasonable accommodation of religious or moral beliefs is required before completing a determination of death using brain death criteria.").

169. See *supra* notes 122-134 and accompanying text (discussing quantitative judgments of futility).

170. Cf. *supra* notes 101-121 and accompanying text (discussing qualitative judgments of futility). But see Stern, *supra* note 50, at 1008 ("[Some scholars] question whether a person insisting on futile treatment has made an informed decision, apparently no matter how much medical knowledge they [sic] have.").

There would be two individuals with identical conditions and prognoses, one of whom would be dead and the other of whom would not only *not* be dead but also would not be futile to treat.¹⁷¹

A separate question, not the subject of this Article, is whether states should accommodate this rejection of the brain-death criterion for death. Commentators advocating such an accommodation¹⁷² seem not to appreciate some of the ramifications of such a position. For example, a particular individual could be considered dead in one state and not in another, even though her condition would not have changed.¹⁷³ Even if the counterintuitive implications of a person's being able to opt out of a particular definition of death are not fatal to allowing such an exception, and even if it is within the state's prerogative to create such an exception, individuals should not deserve to be able to define what constitutes death just because they have lived according to certain precepts during their lifetimes. So, too, individuals should not be allowed to define futility for themselves merely because they have lived in accord with a certain tradition.¹⁷⁴ While their having lived according to a certain custom might establish the sincerity of their beliefs, it would not establish their right to define important medical or legal concepts as they see fit.

Perhaps it would seem surprising that the state would be in a position to declare who is and who is not dead, because this might appear quite straightforwardly to be a medical matter. Yet, as the Supreme Court of Washington has observed, "Death is both a legal and medical question."¹⁷⁵ Courts have suggested that it is for the law to determine what constitutes death, which means that either a court or a legislature could make the relevant decision.¹⁷⁶

171. Some commentators would not classify this situation as problematic. *See, e.g.*, Stern, *supra* note 50, at 1008 ("People who have lived their whole lives in accordance with a religious tradition should be accorded the courtesy—dare I say respect—of living their last hours and days in accordance with that tradition.").

172. *See, e.g.*, Goldberg, *supra* note 166, at 1243 (advocating the view that the individual's death preferences should be respected).

173. *See* Annas, *supra* note 91, at 878 ("In 1981, there were seven different brain death statutes. So theoretically (but not really) you could put someone in an ambulance in California and drive them across the country to Pennsylvania and they'd be dead, alive, alive, dead, alive, dead, dead, alive, dead, dead, and arrive in Pennsylvania alive.").

174. *But see supra* note 171.

175. *In re Welfare of Bowman*, 617 P.2d 731, 734 (Wash. 1980) (en banc); *accord* Swafford v. State, 421 N.E.2d 596, 601 (Ind. 1981) ("The determination of what condition constitutes death, however, can no longer be regarded exclusively as a medical question.").

176. *Bowman*, 617 P.2d at 732 ("We hold that it is for law to define the standard of death."). In some states, courts have made the decision. *See, e.g.*, *Commonwealth v. Goston*, 366 N.E.2d 744, 748-49 (Mass. 1977) (upholding the use of the brain-death definition to determine "death"); *Bowman*, 617 P.2d at 732 ("We hold . . . that the brain death stan-

If a legislature can adopt a definition of death, it can also modify that definition,¹⁷⁷ as long as constitutional guarantees are not thereby violated.¹⁷⁸ Some commentators suggest that legislatures should be permitted to adopt an upper-brain death criterion for death.¹⁷⁹ Thus, an individual who had suffered neocortical death could be considered legally dead.

This recommendation is more easily understood if one considers that the brain dies in stages, with the upper brain dying first.¹⁸⁰ Once the upper brain dies, the person will be without consciousness.¹⁸¹ Commentators suggest that because consciousness and self-awareness

dard should be adopted.”). In other states, legislatures have decided. See, e.g., ALA. CODE § 22-31-1(b) (1990) (offering criteria for death); CAL. HEALTH & SAFETY CODE § 7180(a) (West Supp. 1997) (offering criteria for death); FLA. STAT. ANN. § 382.009(1) (West 1993) (discussing when brain death criteria are applicable); MICH. COMP. LAWS ANN. § 333.1033 (West 1992) (defining death); MONT. CODE ANN. § 50-22-101 (1995) (defining death); N.C. GEN. STAT. § 90-323 (1993) (defining brain death); OHIO REV. CODE ANN. § 2108.30 (Anderson 1994) (explaining when death has occurred). See also *supra* note 162 for the language of these statutes.

177. See, e.g., *In re T.A.C.P.*, 609 So. 2d 588, 593 (Fla. 1992) (discussing the 1988 Florida Legislature’s consideration of a bill to modify the definition of death); Friedman, *supra* note 118, at 936-37 (discussing a proposal to amend the California definition of death to include anencephaly); Lisa E. Hanger, *The Legal, Ethical, and Medical Objections to Procuring Organs from Anencephalic Infants*, 5 HEALTH MATRIX 347, 352 (1995) (discussing the same proposal); Brandon, *supra* note 47, at 795 (discussing the same proposal); Kathleen L. Paliokas, Note, *Anencephalic Newborns as Organ Donors: An Assessment of “Death” and Legislative Policy*, 31 WM. & MARY L. REV. 197, 206 (1989) (discussing the same proposal).

178. One commentator suggests that if the states’ definitions of “death” vary too broadly, a “federal interest” may ultimately provide an impetus for a constitutional check on the states’ powers of establishing such a definition:

A fixed federal definition of Fourteenth Amendment personhood avoids the possibility of aberrant states adopting extremely narrow or extremely broad definitions of “persons.” . . .

The case for the variable definition of personhood rests on the likelihood that states will not differ significantly in who they consider to be “not dead,” and therefore “persons.” If disagreement between the states is limited to the question of whether a “whole brain” or “upper brain” standard should be applied, the federal interest in imposing a federal standard diminishes.

Douglas O. Linder, *The Other Right-to-Life Debate: When Does Fourteenth Amendment “Life” End?*, 37 ARIZ. L. REV. 1183, 1195-96 (1995).

179. See Ducor, *supra* note 166, at 215 (discussing the adoption of a higher-brain-death definition of “death”); cf. Friedman, *supra* note 118, at 959 (suggesting that legislatures should be allowed to adopt a definition of “death” that would classify anencephalic infants as dead).

180. See DAVID W. MEYERS, MEDICO-LEGAL IMPLICATIONS OF DEATH AND DYING § 2:2, at 12 (1981) (describing the process by which the brain dies).

181. See Paliokas, *supra* note 177, at 202 (“During the brain death period, the brain itself dies in stages with the cerebral or higher function centers, including consciousness and intelligent thought, dying first and the lower centers, including the brain stem, which maintains respiration and circulation, dying last.”).

are the characteristics that make us human,¹⁸² there is an important sense in which individuals without those capacities are already dead.¹⁸³ Precisely because modern technology can keep "individuals" alive even though they will never regain consciousness or, perhaps, have any brain activity at all, it may well be that a new definition of death is necessary.¹⁸⁴

One difficulty posed by adopting a new definition of death is that individuals may incorrectly be diagnosed as dead; such misdiagnoses could result from the difficulties inherent in the new criteria's application.¹⁸⁵ For example, if an upper-brain death criterion of death is adopted, it may be difficult to distinguish between someone in a locked-in state and someone who is neocortically dead.¹⁸⁶ Further,

182. One commentator notes:

According to the [bodily-integrity] concept's dictates, a patient who possesses bodily integrity, either natural or mechanically imposed, but who has lost the capacity for consciousness and self-awareness, remains a live person. Yet such a person has lost all ability to experience the world, including all those experiences that give life its humanity, such as sensation, perception of a self through time, choice between alternative courses of action, reflection, communication, and emotion.

Tom Stacy, *Death, Privacy, and the Free Exercise of Religion*, 77 CORNELL L. REV. 490, 505 (1992); accord *Cruzan* by *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 345 (1990) (Stevens, J., dissenting) ("[F]or patients . . . who have no consciousness and no chance of recovery, there is a serious question as to whether the mere persistence of their bodies is 'life' as that word is commonly understood, or as it is used in both the Constitution and the Declaration of Independence." (emphasis omitted)); Dresser, *supra* note 114, at 662 ("[P]ermanently unconscious patients themselves are incapable of possessing any interests, in the usual meaning of the term." (emphasis omitted)); Schrode, *supra* note 44, at 1644 ("Several commentators have suggested that this standard is problematic because it classifies patients who have lost the capacity for self-awareness and consciousness as being alive, despite the fact that these are the very characteristics that make us human.").

183. See Stacy, *supra* note 182, at 528 ("[T]he permanently unconscious are, like artificially maintained brain-dead patients, already dead."); 2 W. NOEL KEYES, *LIFE, DEATH, AND THE LAW* 646 (1995) (stating that upper-brain death destroys all capacity for conscious thought and is therefore the death of the person).

184. One court has observed:

[W]e are on the threshold of new terrain—the penumbra where death begins but life, in some form, continues. We have been led to it by the medical miracles which now compel us to distinguish between "death," as we have known it, and death in which the body lives in some fashion but the brain (or a significant part of it) does not.

Severns v. Wilmington Med. Ctr., Inc., 421 A.2d 1334, 1344 (Del. 1980) (en banc).

185. Cf. *In re Alvarado*, 550 N.Y.S.2d 353, 354 (App. Div. 1990) (mem.) (vacating an order permitting a hospital to remove life-support systems, because the infant on the systems did not have any indications of brain death).

186. One commentator explains:

A closely related problem is the difficulty of distinguishing between a patient who is neocortically dead and one who exists in the state known as "locked-in syndrome." Those in the latter category have undergone paralysis of all four lower extremities and the lower cranial nerves, yet retain consciousness, and

additional concerns might be raised if there were an appearance of arbitrariness in how death was defined.¹⁸⁷ For example, were death redefined to include anencephalic infants so that their organs might be harvested,¹⁸⁸ public confidence might be undermined in the consistency and nonarbitrariness of the definition of death.

Yet, these arguments prove too much. One of the reasons that brain death was adopted in the first place was to facilitate organ transplants.¹⁸⁹ Thus, it is not clear that changing the definition of death out of a desire to facilitate transplantation would undermine public confidence in that definition. Further, the suggestion is not that upper-brain death be adopted as the definition to enable organs of the permanently unconscious to be transplanted, but merely that the definition of death should be related in a direct and important way to the qualities which make individuals essentially human.¹⁹⁰ Finally, while the possibility of mistakes might give reason for pause, mistakes are made even using the current definition of death.¹⁹¹ In any event, it would seem that adequate safeguards could be developed to prevent misdiagnosis.¹⁹²

Putting aside the controversy surrounding the appropriate definition of death, courts are not consistent with respect to the application of the term "death," even when using the current definition involving whole-brain death. Consider an individual who is completely brain dead and who is being kept "alive" on life support so that her organs can be harvested. Insofar as such an individual is alive, it might seem that the doctors removing her kidneys, rather than the person who

therefore can not [sic] be grouped with neocortically dead patients who have lost all consciousness. Because those suffering from "locked-in syndrome" cannot communicate with others, their condition mimics that of a neocortically dead patient.

Friedman, *supra* note 118, at 961 (footnote omitted).

187. See Brandon, *supra* note 47, at 819 ("Redefining death would create confusion and call into question the validity of brain death criteria: Is society manipulating this most fundamental concept to serve its immediate social needs?").

188. See *id.* at 795 (discussing a proposal to modify the California definition of death to include anencephaly).

189. Robert L. Geltzer et al., *National Conference on Birth, Death, and Law*, 29 JURIMETRICS J. 403, 422 (1989); Goldberg, *supra* note 166, at 1204; James M. Jordan III, Note, *Incubating for the State: The Precarious Autonomy of Persistently Vegetative and Brain-Dead Pregnant Women*, 22 GA. L. REV. 1103, 1162 (1988); Paliokas, *supra* note 177, at 204.

190. See 2 KEYES, *supra* note 183, at 646 ("It would appear that the concept of death based upon the neocortex may be the most humane test possible to differentiate us from animals.").

191. See, e.g., *In re Alvarado*, 550 N.Y.S.2d 353, 354 (App. Div. 1990) (mem.) (holding that the infant was wrongly diagnosed as dead).

192. See Strasser, *supra* note 107, at 790 (suggesting that if proper procedures are followed, misdiagnosis can be avoided).

had brought about the patient's condition, would be "killing" the patient.¹⁹³ Not surprisingly, courts have not held doctors responsible for the deaths in these kinds of cases, and they have upheld the murder convictions of the individuals who had caused the victims' brain deaths.¹⁹⁴ Yet, if indeed the "patient" is "dead" even before "life-support" has been terminated, it would seem that the dead body should be turned over for burial rather than kept "alive" for the possible harvesting of organs.¹⁹⁵ Court decisions on these matters yield the conclusion that the same individual can be legally dead for certain purposes but not for others.¹⁹⁶

G. *The Futility of Treating Those Who Are Upper-Brain Dead*

Whether one believes that the appropriate definition of death involves whole-brain or upper-brain death, a separate question is whether treatment of individuals who have suffered upper-brain death is nonfutile. Even given the currently accepted definition of brain death,¹⁹⁷ the state might declare certain individuals legally dead (e.g., individuals with no brain functioning whatsoever), while declaring other individuals alive but not appropriate candidates for treatment (e.g., those who have no hope for restoration of upper-brain functioning).¹⁹⁸

193. See *Cranmore v. State*, 271 N.W.2d 402, 427 (Wis. Ct. App. 1978) (discussing the defendants' suggestion that "the death of Dennis O'Bradovich [the victim] was caused by the actions of his attending physicians in performing a nephrectomy (removal of kidneys) and in discontinuing the respirator and the administration of pressor drugs (artificial aids to maintain blood pressure in the body).").

194. See *People v. Bonilla*, 467 N.Y.S.2d 599, 609 (App. Div. 1983) (upholding such a conviction, even though the victim was artificially maintained to harvest the kidneys and the spleen), *aff'd sub nom. People v. Eulo*, 472 N.E.2d 286 (N.Y. 1984); *Cranmore*, 271 N.W.2d at 428 (upholding such a murder conviction).

195. But see *Strachan v. John F. Kennedy Mem'l Hosp.*, 507 A.2d 718, 725 (N.J. Super. Ct. App. Div. 1986) ("Before the life support systems were disconnected, there was no dead body to be claimed for burial."), *aff'd in part, rev'd in part*, 538 A.2d 346 (N.J. 1988). The New Jersey Supreme Court reversed *Strachan* on the "dead"/"alive" issue, holding that the hospital had a duty to deliver the "dead" body to the patient's parents as soon as the patient had been declared brain dead. *Strachan*, 538 A.2d at 351.

196. Cf. Goldberg, *supra* note 166, at 1244 ("Both the medical and legal profession seem equipped to apply different definitions [of death] in different contexts.").

197. See *supra* notes 161-162 and accompanying text.

198. See Schneiderman et al., *supra* note 50, at 952 ("In keeping with the qualitative notion of futility we propose that any treatment that merely preserves permanent unconsciousness or that fails to end total dependence on intensive medical care should be regarded as nonbeneficial and, therefore, futile."). But see Lantos et al., *supra* note 70, at 83 (suggesting that "prolonged nutritional support for patients in a persistent vegetative state" is not futile).

When discussing why it is futile to treat someone who has suffered upper-brain death, numerous reasons might be offered, including the inefficacy of the treatment¹⁹⁹ or the fact that the treatment will not benefit the patient.²⁰⁰ Indeed, when considering someone who is not and never will be conscious, it is difficult to understand how treatment will benefit that patient,²⁰¹ because she will never have any knowledge or understanding of what has or has not been done and will never feel any pleasure or pain in any event.²⁰²

An additional reason offered to support the nontreatment of the permanently unconscious is that therapy for such individuals seems to be a poor allocation of scarce resources. However, the futility and the resource-allocation arguments are separate and distinct, and they should not be conflated.

H. Rationing

One issue involves determining which treatments are futile, and a different issue involves determining which treatments should be rationed. Rationing and futility judgments are distinguishable: The former involves decisions about which beneficial treatments will not be provided, while the latter involves judgments about which treatments will not in fact provide benefit.²⁰³

It is important not to conflate these issues by, for example, including considerations of economic concerns within the definition of medical futility²⁰⁴ or by, perhaps, using futility as a mask to justify a

199. See *supra* notes 49-56 and accompanying text (discussing the futility-as-having-no-effect definition of futility).

200. See *supra* notes 57-78 and accompanying text (discussing the net-benefit definition of futility).

201. See Ann MacLean Massie, *Withdrawal of Treatment for Minors in a Persistent Vegetative State: Parents Should Decide*, 35 ARIZ. L. REV. 173, 204 (1993) ("Anyone suffering a total loss of consciousness is incapable of 'benefitting' from continued life support.").

202. See Angell, *supra* note 53, at 512 ("Because she was in a persistent vegetative state, Mrs. Wanglie was incapable of suffering.").

203. One commentator explains the distinction as follows:

When a given treatment is deemed to be futile, the implication is that it has no therapeutic benefit. Futility decisions do not rest on the fact that there are scarce resources. Rationing, however, implies that the treatment may provide a therapeutic benefit, but concerns of cost and allocation of limited resources dictate that the treatment not be given.

Smith, *supra* note 53, at 15 (footnotes omitted); accord Schneiderman & Jecker, *supra* note 58, at 437 ("It is particularly important . . . to distinguish futility (implying no apparent therapeutic benefit) from rationing (acknowledging therapeutic benefit but raising questions about cost-worthiness)."). But see Scofield, *supra* note 27, at 929 (suggesting that futility decisions and rationing decisions are not distinguishable).

204. See Boozang, *supra* note 86, at 75 ("There is great danger in confusing the issues of physiologically futile treatment and allocation of scarce health care resources.").

policy that is really economically driven.²⁰⁵ Further, it is important not to be reductionistic and combine notions of futility and rationing by suggesting that they both involve the issue of whether the patient will in fact receive the treatment,²⁰⁶ because the *justification* for not offering a treatment would be quite different depending upon whether futility or rationing was involved.

When rationing is discussed, two separate questions must be addressed: (1) whether a particular treatment will be provided, and (2) who will pay for that treatment if it is provided.²⁰⁷ Some commentators suggest that even futile care should be provided as long as society does not have to pay for it.²⁰⁸ However, such an analysis may be too superficial, because indirect costs may not be counted in such calculations.²⁰⁹ Thus, if insurance must pay for care that is futile, other types of care might have to be sacrificed.²¹⁰ Even if care did not have to be

205. See Loewy & Carlson, *supra* note 93, at 430 ("It is, however, another matter to base such decisions on an excuse of futility than to grapple with the question of discontinuing treatment in some persons because it is both unlikely (albeit not impossible) to succeed and is, furthermore, terribly expensive.").

A separate question involves how expensive it will be to give futile care. See Sorum, *supra* note 130, at 622 (suggesting that offering one kind of futile care would involve "potentially enormous psychological and economic costs").

206. See *Goepel v. Mail Handlers Benefit Plan*, Civ. A. No. 93-3711 (JEI), 1993 WL 384498, at *1 (D.N.J. Sept. 24, 1993) ("‘Rationing’ is an ugly word when used to describe the process by which society decides what medical procedures and services will generally be made available to the public."), *vacated sub nom.* *Goepel v. National Postal Mail Handlers Union*, Div. of LIUNA, 36 F.3d 306 (3d Cir. 1994).

207. Cf. Boozang, *supra* note 86, at 75 ("The need for reallocation of health care resources may be an appropriate reason for society to consider whether it is willing to pay for futile treatment for a dying patient.").

208. See Goldberg, *supra* note 166, at 1246 ("The simplest answer is that the individual who desires the continued care should bear the burden of paying for it."); Morreim, *supra* note 25, at 915 ("If our objective in these difficult areas is to respect citizens' diverging viewpoints, we must draw stringent limits on the amount of funding that we conscript from unwilling citizens to fund exotic health care."); Veatch & Spicer, *supra* note 51, at 30 ("[W]e see no reason to prohibit private arrangements to provide it, as long as these arrangements do not draw on resources needed for others."); Schrode, *supra* note 44, at 1666 ("Arguably, it is unjust to allow public funds to sustain the biological lives of some patients without regard to cost or quality of life, while others have no access to even the most basic necessities. If individuals . . . [can afford] nonbeneficial care, they will be allowed to [finance it]." (footnote omitted)).

209. See Morreim, *supra* note 25, at 912 ("Ultimately, the money [for exotic care] comes from private individuals who pay premiums either directly through their pockets, or indirectly through taxes, consumer prices, and the diminution of wages and other employee benefits that inevitably accompanies a rise in health premiums.").

210. See *id.* at 917-18 ("If a health plan is required to provide exotic care on the massive scale implied by the Baby K case, [insurance] subscribers would have substantially less access to the 'basic care' In short, subscribers could expect to wait longer for routine appointments and have substantially fewer choices of providers, tests, and treatments."); cf. Veatch & Spicer, *supra* note 51, at 30 ("[E]fficiency and equity require that coverage be

sacrificed, and patients did not have to forego possibly beneficial treatments, there would still remain the difficulty of doctors' prescribing treatments that they themselves consider futile.²¹¹

I. Who Defines Futility

Some commentators contend that it is inappropriate for individual doctors to make decisions about what constitutes futile treatment. These commentators base their belief on two factors: (1) doctors tend to overestimate the difficulties associated with living with particular handicaps,²¹² and (2) doctors may allow nonmedical factors like race to play a role in decisionmaking.²¹³ Some of these theorists suggest that if medical societies, rather than individual doctors, decided which treatments were futile, it would be less likely that mistaken policies would be adopted.²¹⁴

Yet, if the relevant decisions were made by medical communities, the difficulties posed by individual doctors' making such decisions

excluded [from patients in a persistent vegetative state] in order to allocate those resources to those who have stronger moral claims."); Dzielak, *supra* note 62, at 760 ("[F]utile death-delaying treatment places a great financial burden on society. Death-delaying medical treatment for permanently vegetative patients costs approximately \$7 billion in resources annually." (footnote omitted)).

211. See *infra* notes 238-245 and accompanying text (discussing physicians treating patients in a manner contrary to their professional consciences).

212. Cf. Boozang, *supra* note 86, at 37-38 ("Evidence indicates . . . that the physician's judgment about the patient's quality of life frequently clouds his determination of whether CPR should be provided to the patient."); Scofield, *supra* note 27, at 934 ("[T]here is some reason to believe that attitudes and beliefs about persons with disabilities can and do affect decisions about the sort of treatment such persons are to receive, including decisions about medically futile treatment."); Sorum, *supra* note 130, at 623 ("Physicians tend . . . to underestimate how the patient rates his or her quality of life.").

213. See Boozang, *supra* note 86, at 38 ("[T]he presence of nonmedical factors such as mental retardation, dementia, age, institutionalization, or a history of violent crime and drug abuse have been found to affect physician decisions to resuscitate patients."); Smith, *supra* note 53, at 3 ("[E]xtraneous factors such as race, wealth, gender, and age of the patient, as well as judgments on the quality of the patient's life and concerns with cost containment, may cloud a physician's determination to withhold or withdraw treatment."); Stuart J. Youngner, *Medical Futility and the Social Contract (Who Are the Real Doctors on Howard Brody's Island?)*, 25 SETON HALL L. REV. 1015, 1021 (1995) ("A recent study . . . found that the non-white race of the patient independently predicted a futility judgment resulting in a DNR [do-not-resuscitate] order.").

214. See, e.g., Crossley, *supra* note 29, at 200 ("[S]ome commentators suggest that the development of standards regarding futile treatment should proceed on an institutional basis, for example, by professional medical societies or hospital ethics committees. These bodies are judged less likely to be influenced by objectionable biases." (footnotes omitted)); Miles, *supra* note 69, at 881 ("Professional societies must assume a leading role in proposing [a] standard of care [that will serve to define medical futility], which in turn must face and survive public scrutiny and debate." (footnote omitted)).

might simply be replicated on a larger scale.²¹⁵ If, indeed, there is a generalized bias within the profession, it is not at all clear that a general consensus that a treatment was futile would establish that the treatment was in fact futile.²¹⁶

Recognizing that there may be a bias within the profession, some commentators suggest that society as a whole should decide which treatments are futile.²¹⁷ Yet, the tendency to undervalue the lives of individuals with disabilities might be something of which society as a whole is guilty.²¹⁸

Individual doctors, medical societies, and even society as a whole may undervalue the lives of individuals with particular disabilities; this does not, however, establish that *no* decisions about the definition of futility can be made. If it is true, for example, that people without any upper-brain activity simply have *no* consciousness,²¹⁹ then one would be hard-pressed to charge that there may be a serious undervaluing of what it is like for such a person to live. While the tendency to undervalue the lives of individuals with disabilities underscores the need to establish a very low level below which treatment would be deemed futile,²²⁰ it is neither impossible to set such a standard²²¹ nor impossible for physicians to apply it.²²² However, it will be important to be vigilant to assure that the official standards are in fact applied, whatever they might be.²²³

215. See Crossley, *supra* note 29, at 200 (stating that critics contend that "delegating those decisions to groups of medical professionals still grants too great a prerogative to groups whose values may depart from societal values").

216. This has not been appreciated by some commentators. See, e.g., Shiner, *supra* note 42, at 846 ("The refusal of all available medical providers to consider providing allegedly futile treatment may signal a medical consensus that such treatment truly is futile.").

217. Schrode, *supra* note 44, at 1613 ("Developing an appropriate policy for permanently unconscious patients requires a social consensus.").

218. See Orentlicher, *supra* note 40, at 69 ("When persons without disabilities are asked to estimate the quality of life of persons with disabilities, their estimates are often considerably lower than the ratings given by persons with disabilities when they are asked to evaluate their own quality of life.").

219. See *supra* note 181 and accompanying text.

220. Cf. Orentlicher, *supra* note 40, at 72 ("What would constitute a reasonable minimum level of benefit, like many other legal standards, is not easily reduced to a precise formula.").

221. Cf. Schneiderman et al., *supra* note 50, at 952 (suggesting that some "sorts of qualitatively poor results fall outside the range of the patient's autonomy and need not be offered as options").

222. Cf. Daniel Callahan, *Medical Futility, Medical Necessity: The Problem Without a Name*, HASTINGS CENTER REP., July-Aug. 1991, at 30, 32 (advocating that physicians be allowed to make decisions "on the basis of societally generated standards").

223. Cf. *In re Finn*, 625 N.Y.S.2d 809, 812 (Sup. Ct.) (explaining that two physicians claimed that treatment of an individual with an I.Q. of approximately 20 would be futile, even though there was "no evidence before the court, never mind evidence demonstrating

III. AUTONOMY

Many debates about the concept of medical futility at least implicitly involve the concern that patient autonomy will be sacrificed if medical futility is to be given any substantive content at all.²²⁴ Yet, patient autonomy is not endangered by giving futility substantive content as long as the proper scope of patient autonomy is understood, the meaning of futility is not overinclusive, and the justification for the definition does not itself undermine futility.

A. *Patient Versus Physician*

The futility debate is sometimes characterized as simply a decision about whether the doctor's or the patient's values will triumph.²²⁵ Such a characterization is misleading in a number of respects. It is at best unhelpful to suggest that the debate over futility is a dispute between the doctor and her patient, because it may in fact be others who are setting the criteria for futility—medical boards, Congress, an administrative agency, the American Medical Association, or society at large.²²⁶

Consider a patient who, while still competent, had expressed a desire to receive treatment regardless of her condition or prognosis. At least one issue would involve how such a statement should be

to a reasonable medical certainty, that [the individual's] *present medical condition* would make CPR a medically futile treatment"), *modified sub nom.* Finn v. Leonard C., 634 N.Y.S.2d 262 (App. Div. 1995).

224. See Shiner, *supra* note 42, at 842 ("Recognizing futility as a legal concept would seriously undermine patients' rights").

225. Cf. Boozang, *supra* note 86, at 71 ("Vesting in the physician the power to arbitrate what constitutes reasonable patient decisions and rationales which deserve respect . . . establishes as superior the physician's values, culture, beliefs and decision-making process.").

226. See, e.g., 22 C.F.R. § 142.62 (1997) (Department of State provision prohibiting discrimination against handicapped persons); 45 C.F.R. § 1340.15 (1996) (Department of Health and Human Services regulations implementing the Child Abuse Prevention and Treatment Act, 42 U.S.C.A. § 5106g (West Supp. 1997)); 45 C.F.R. § 1340 app. (1996) (Interpretative Guidelines Regarding 45 C.F.R. § 1340.15—Services and Treatment for Disabled Infants); Barnett v. Kaiser Found. Health Plan, Inc., 32 F.3d 413, 415 (9th Cir. 1994) (discussing the role of the Permanente Medical Group's Liver Transplant Advisory Board, a committee of liver specialists, in deciding who should be candidates for organ transplant); Conservatorship of Drabick, 245 Cal. Rptr. 840, 845 (Ct. App. 1988) (discussing the AMA view on treating the irreversibly comatose); Brandon, *supra* note 47, at 811-12 (suggesting that the amended federal Child Abuse Prevention and Treatment Act allows treatment to be withheld from anencephalic infants); cf. Morreim, *supra* note 25, at 925 (arguing that EMTALA and the ADA could be narrowly interpreted with respect to the health care they require to be provided).

treated.²²⁷ Certainly, her expressed desires could be respected.²²⁸ However, if those wishes are not to be honored, some justification would seem to be required, because such a refusal *appears* to involve a clear disregard of the patient's autonomy.

Patients do not have a right to demand treatment under any and all circumstances, so it need not be a denial of autonomy to refuse to accede to *certain* patient requests.²²⁹ The difficulty will be in deciding which requests may be denied (e.g., whether a request could be denied if the patient would not be able to appreciate the life extension were it given).²³⁰

Any policy limiting patient autonomy must be narrowly drawn. Otherwise, the policy might be used to override the patient's wishes with respect to nontreatment²³¹ or with respect to receiving painful therapy that might afford additional days or weeks of conscious life.²³² It is suggested here that the concept of futility should be robust enough to honor a request for nontreatment if, indeed, the requesting patient could reliably be predicted never to regain consciousness,²³³ but weak enough to classify as nonfutile those treatments that may yield extra conscious life.²³⁴

Some commentators suggest that the real issue is not whether a particular treatment is futile but, rather, who should decide whether the particular treatment should be administered.²³⁵ This is correct to some extent, in that for a certain range of choices the patient (or surrogate) should be making the relevant decision.²³⁶ The preferable, more finely grained approach, however, allows the patient or sur-

227. See Linder, *supra* note 178, at 1201-02 (suggesting that the clarity with which the patient expresses a desire to continue vegetative existence may play a role in eventual decisionmaking).

228. See Angell, *supra* note 53, at 512 (suggesting that absent a change in the definition of "death," autonomous wishes may have to be accepted).

229. *But see supra* note 224.

230. *Cf.* Rhoden, *supra* note 32, at 1314 (attaching great importance to the ability of the dying patient to appreciate the additional days that treatment could offer).

231. *Cf. In re Fiori*, 673 A.2d 905, 910 (Pa. 1996) ("Courts have unanimously concluded that this right to self-determination does not cease upon the incapacitation of the individual.").

232. See *supra* notes 131-134 and accompanying text (discussing the potential value of extending life for a few days).

233. *Cf. supra* note 164 (explaining how bodily organs may survive and function indefinitely after brain death).

234. *Cf. supra* note 63 and accompanying text (noting that the *Baby K* ruling requires care to be provided to all patients whose lives might be extended).

235. See Angell, *supra* note 53, at 511 (suggesting that the important consideration is the decisionmaker rather than the decision's content).

236. See *supra* notes 82-83 and accompanying text (discussing the importance of respecting patient autonomy in certain instances).

rogate to make some choices but *not* those that fall in the range involving futile treatment (i.e., where futility has been appropriately defined).²³⁷

It is simply incorrect to suggest that the futility debate is a battle pitting the patient's autonomy against the physician's conscience.²³⁸ Patient autonomy does not give patients the right to make *all* decisions, including, for example, the appropriate criteria for death.²³⁹ Thus, as long as the concept is limited to a narrow range of treatments that offer no hope of restoring consciousness, one should not think that patient autonomy includes the right to define futility.

Commentators who claim that physicians cannot be forced to administer treatment when doing so would violate their consciences overstate the case, because the physician's conscience-based objection must be in accord with generally accepted medical standards.²⁴⁰ If the

237. See Jecker & Pearlman, *supra* note 104, at 1142 ("[I]t is not paternalistic to refuse to honor a patient's request for *futile* treatment, because patients are not considered entitled to futile treatment in the first place.").

238. Cf. *United States v. George*, 239 F. Supp. 752, 754 (D. Conn. 1965) ("To require these doctors to ignore the mandates of their own conscience, even in the name of free religious exercise, cannot be justified under these circumstances. The patient may knowingly decline treatment, but he may not demand mistreatment."); *Findlay v. Board of Sup'rs*, 230 P.2d 526, 532 (Ariz. 1951) (Phelps, J., specially concurring) ("It would not only not be professional but it would be highly unprofessional for a physician to assist in the performance of an operation which he believed to be unnecessary or unwise to perform at that time."); *Conservatorship of Morrison*, 253 Cal. Rptr. 530, 531 (Ct. App. 1988) ("[W]e hold that a conservator can authorize the removal of a nasogastric feeding tube from a conservatee who is in a persistent vegetative state, but cannot [necessarily] require physicians to remove the tube against their personal moral objections."); *Grace Plaza, Inc. v. Elbaum*, 588 N.Y.S.2d 853, 859 (App. Div. 1992) ("While we recognize the right of a patient to control the course of his or her treatment, we do not recognize any right to force a health-care provider to render treatment which is contrary to his or her own conscience."), *aff'd*, 623 N.E.2d 513 (N.Y. 1993); Smolin, *supra* note 87, at 990 ("[P]hysicians or other medical care providers generally should not be penalized for refusing to provide treatments that violate their religious conscience."); Dzielak, *supra* note 62, at 759 ("Compelled futile medical treatment compromises physician ethics and morals. Physicians have the responsibility to abstain from administering or continuing futile treatment." (footnotes omitted)); Nealy, *supra* note 22, at 157 ("Medical ethics do not permit patients to require a physician to render treatment that, in the physician's judgment, would be futile or otherwise medically inappropriate. It is ethical for a physician to refuse to accede to such a demand.").

239. See *supra* note 167 and accompanying text (noting that it is the duty of the medical profession to determine the criteria for death).

240. See *In re Farrell*, 529 A.2d 404, 412 (N.J. 1987) ("[A] patient has no right to compel a health-care provider to violate generally accepted professional standards."); Daar, *supra* note 48, at 1246 ("Assertion of a physician's professional conscience . . . simply means that a physician will be accorded the right to choose whether to initiate or continue a course of treatment that offends some deeply held personal beliefs.").

professional's conscience dictates something that is not in accord with those standards, the conscience must then be overridden.²⁴¹

Some contend that allowing the patient to have total control over medical decisionmaking would demean the medical profession.²⁴² Yet, concerns about the integrity of the medical profession have not been deemed sufficiently weighty to justify overriding patient autonomy in withdrawal and refusal of treatment cases.²⁴³ Indeed, it would be difficult to argue that concerns of medical integrity should have any bearing in the context of withdrawal and refusal; such an argument might mean that the integrity of the medical profession would be upheld at the cost of patients' lives.²⁴⁴ Of course, as a practical matter, physicians tend not to hide behind their professional consciences in order to avoid treating patients; in fact, they seem to treat even when their consciences dictate otherwise.²⁴⁵

Maryland and Virginia have statutorily declared that physicians need not provide treatment that they believe to be inappropriate.²⁴⁶ However, the relevant statutes provide that the patient should be transferred elsewhere rather than receive no care at all.²⁴⁷ Certainly,

241. See Levine, *supra* note 49, at 101 ("When the standard of care demands that a treatment be provided for a certain medical condition under a certain set of circumstances, barring any reasonable alternative or a transfer of the patient, the physician must provide that treatment . . . even though the provision of treatment would violate the physician's conscience." (footnote omitted)).

242. See Daar, *supra* note 48, at 1245 (suggesting that leading doctors to see themselves as "medical vending machines" would have bad effects (internal quotation marks omitted)); Levine, *supra* note 49, at 83 ("By giving the patient sole authority to determine whether treatment is futile, the shared decisionmaking model of the physician-patient relationship is reduced to little more than vending machine medicine." (internal quotation marks omitted)).

243. See Goldberg, *supra* note 166, at 1240 ("Another state interest relevant in withdrawal or refusal of treatment cases is the ethical integrity of the medical profession. . . . Yet, the state interest in the medical profession's ethical integrity has not been sufficient to override a particular individual's wishes in withdrawal or refusal of treatment cases.").

244. See Veatch & Spicer, *supra* note 51, at 27 (arguing that "support for professional integrity" does not permit society to "grant[] the authority to make decisions about whether someone else's life is worth prolonging").

245. Consider this example:

Fourteen hundred doctors and nurses at five major hospitals were asked about their treatment of terminally ill patients: fully seventy percent of the resident doctors said that they themselves *overtreated* such patients, against their own conscience, and against what they knew to be the patients' interests and wishes. Four times as many of those surveyed thought that doctors *overtreated* dying patients as that they *undertreated* them.

RONALD DWORKIN, *LIFE'S DOMINION* 183 (Vintage Books 1994) (1993).

246. See MD. CODE ANN., HEALTH-GEN. I § 5-611(a) (1994); VA. CODE ANN. § 54.1-2990 (Michie 1994).

247. MD. CODE ANN., HEALTH-GEN. I § 5-613(a); VA. CODE ANN. § 54.1-2987; *accord* Daar, *supra* note 58, at 231 ("[I]n fact, neither Virginia nor Maryland law permits a physician to

this is reasonable if the patient can be transferred.²⁴⁸ If transfer is not possible,²⁴⁹ however, the physician may be forced to continue treatment.²⁵⁰

Suppose that treatment for a patient would clearly be futile. A separate question is whether the decision not to treat must be discussed with the patient or the family.²⁵¹ Some commentators suggest that because futility is a medical decision, no such discussions are required.²⁵² That may be true insofar as the only concern is whether treatment will ultimately be given. Yet, there are a number of possible benefits that might be realized by talking the decision over with the patient or the family. First, the discussion would accord respect to patients or their families and might promote confidence in the medical profession. Second, the family might come to understand the in-

unilaterally terminate care against the wishes of the patient or surrogate."); Shiner, *supra* note 42, at 845 ("The Virginia and Maryland health care decisions acts respond to this concern by providing for transfer of the patient when physicians determine that requested treatment is inappropriate.").

248. See *Conservatorship of Morrison*, 253 Cal. Rptr. 530, 534 (Ct. App. 1988) ("The prevailing viewpoint among medical ethicists appears to be that a physician has the right to refuse on personal moral grounds to follow a conservator's direction to withhold life-sustaining treatment, but must be willing to transfer the patient to another physician who will follow the conservator's direction."); Veatch & Spicer, *supra* note 51, at 24 ("The first option [for a clinician who feels that some treatment violates his conscience] . . . is to find some other clinician who can provide the care without feeling personally violated. That is clearly the wisest course, both from the point of view of the professional and that of the patient.").

249. Shiner, *supra* note 42, at 845 (suggesting that "transferring a patient is not always an available option").

250. MD. CODE ANN., HEALTH-GEN. I § 5-613(a)(3) ("Pending the transfer, [a health care provider who believes treatment is inappropriate shall] comply with an instruction of a competent individual."); see also Veatch & Spicer, *supra* note 51, at 25 (suggesting that treatment must be given, even if contrary to a physician's conscience, where transfer is not possible); cf. *Grace Plaza, Inc. v. Elbaum*, 588 N.Y.S.2d 853, 858 (App. Div. 1992) ("[N]o medical professional may be compelled to violate his own medical ethics by being forced to remove a feeding tube from an incompetent patient, unless the patient's conservator proves the total unavailability of any physician willing to do so."), *aff'd*, 623 N.E.2d 513 (N.Y. 1993).

251. See Bennett, *supra* note 112, at 39 ("The AMA concludes that in the unusual circumstance where resuscitation is deemed medically futile by the attending physician, *even if previously requested by the patient*, resuscitation may be withheld. However, this does not discharge the physician's obligation to discuss these treatment decisions with the patient."); Jecker & Pearlman, *supra* note 104, at 1143 ("[P]hysicians might note that even if they are not under a duty to obtain permission from patients, it is incumbent on them to inform patients (or surrogates) when, and to explain to them why, futility judgments are made.").

252. J. Chris Hackler & F. Charles Hiller, *Family Consent to Orders Not to Resuscitate: Considering Hospital Policy*, 264 JAMA 1281, 1282 (1990). But see Bennett, *supra* note 112, at 45 ("[F]utility decisions should be left to the physicians, although mandatory communication and dialogue must exist between physician and patient, family, or surrogate.").

evitability of death²⁵³ or, perhaps, might want to seek another opinion before accepting the prognosis.²⁵⁴ Finally, there might be many fewer patients and families demanding treatment if explanations were offered by physicians.²⁵⁵ Studies indicate that in many cases where the doctor believed resuscitation would not be appropriate, the patient would have refused resuscitation had she been informed of the doctor's opinion and given the opportunity to make that decision.²⁵⁶ Studies also indicate that patients themselves often want to have those discussions.²⁵⁷

B. Mischaracterizations of Autonomy

Some commentators suggest that patient autonomy does not include the right to demand futile treatment, because patient autonomy only includes the right to make a rightful medical decision.²⁵⁸ While the conclusion is correct, the analysis and justification are not, for they could seriously undermine patient autonomy if the "rightful decisions" category were too narrowly construed.²⁵⁹ For example, one might imagine a patient not being allowed to choose a plausible, less invasive procedure because, according to the doctor, that was not a rightful choice.

253. Bennett, *supra* note 112, at 42 ("Patients and their families have not had such an education and may be dealing, for the first time, with life, its value, its quality, confrontation with death, and the dilemmas of profound emotional and/or physical suffering.").

254. See Smith, *supra* note 53, at 19 ("Informing the patient and his family of the decision not to administer treatment on the grounds of futility helps patients and families cope with the inevitability of death, and permits them to seek a second opinion or alternative medical care." (footnotes omitted)); cf. Council on Ethical & Judicial Affairs, *supra* note 48, at 1870 ("[W]hen there is adequate time . . . the physician should inform the patient, or . . . [her] surrogate, of the content of [a] DNR order, as well as the basis for its implementation The physician also should be prepared to discuss appropriate alternatives." (footnote omitted)).

255. Cf. Stuart J. Youngner, Editorial, *Futility in Context*, 264 JAMA 1295, 1296 (1990) ("Futile resuscitation may also be expected or demanded by patients and families because they do not have all the facts or have not digested them.").

256. See Boozang, *supra* note 86, at 58 ("[P]atient studies indicate that most patients for whom physicians would recommend against CPR would decline resuscitation if properly informed and given the opportunity to choose."); cf. Bonanno, *supra* note 45, at 169 ("[M]uch of the futility debate may be circumvented by improved doctor-patient communications about the goals of medical treatment.").

257. Cf. Council on Ethical & Judicial Affairs, *supra* note 48, at 1869 ("[M]ost patients wish to discuss their preferences about resuscitation with their physicians.").

258. See Smith, *supra* note 53, at 21 ("[P]atient rights of autonomy or self-determination are abridged, not when there is a denial of opportunities to make *any* medical decision, but rather when there is a denial of an opportunity to make 'a *rightful* medical decision.'").

259. See John F. Peppin, *Physician Neutrality and Patient Autonomy in Advance Directive Decisions*, 11 ISSUES L. & MED. 13, 20 (1995) ("If autonomy is defined in terms of honoring only choices that conform to a set standard, how is this autonomous?").

Other commentators suggest that patient autonomy is not denied by refusing to give patients futile treatment. Rather, they argue, autonomy involves the right to be free from interference and thus does not require that one receive desired, but futile, care.²⁶⁰ Yet, the same argument could be used to justify one's not receiving treatment that would effectively restore "normal" functioning. While these theorists are correct that patient autonomy does not include the right to futile treatment, their analyses are so potentially destructive of patient autonomy that they must be avoided, even at great cost.

C. Humanitarian Concerns

Some commentators offer a much different analysis of why patients should receive futile treatment if they so desire. Basically, they argue that such treatment should be offered if only to promote the psychological welfare of the patient²⁶¹ or the patient's family by, for example, helping them come to terms with their loss.²⁶²

Consider someone in a permanent vegetative state. Although bodily functions like heartbeat and pulmonary ventilation are maintained internally, there is no consciousness,²⁶³ appearances to the

260. See Myerberg, *supra* note 19, at 439-40 ("Autonomy is classically described as a negative-freedom from interference, not as a positive-freedom to receive or be given something. When a person demands that all possible medical care be given to sustain life . . . she or he is asking to be given something positive in the name of autonomy." (footnote omitted)). But see Allan S. Brett & Laurence B. McCullough, *When Patients Request Specific Interventions: Defining the Limits of the Physician's Obligation*, 315 NEW ENG. J. MED. 1347, 1347 (1986) ("[T]he idea of positive rights in the physician-patient context—the right that something be done—endorses the patient's right to select a particular intervention and implies a co-existing obligation of the physician to make that intervention available. The principle of respect for autonomy also justifies positive rights.").

261. Cf. Boozang, *supra* note 86, at 70 ("The physician's primary concern for the dying patient who demands futile CPR because she refuses to acknowledge her impending death should be her psychological well-being. The patient's right to be the ultimate decision-maker about her treatment cannot disappear simply because she is extremely ill or dying." (footnote omitted)).

262. See Loewy & Carlson, *supra* note 93, at 429-30 ("To continue treatment that causes the patient no suffering but that prolongs life for a reasonable length of time while those concerned with the patient come to terms with the situation should not be morally offensive."); Schneiderman et al., *supra* note 50, at 953 ("[A] physician may . . . [keep a patient alive] on compassionate grounds, when temporary continuance of biologic life achieves goals of the patient or family."); Schrode, *supra* note 44, at 1648 ("[I]t is appropriate to sustain the biological life of a permanently unconscious patient for a short time while the family comes to terms with the diagnosis.").

263. See *In re Guardianship of Myers*, 610 N.E.2d 663, 670 (Ohio Ct. C.P. 1993) ("The diagnosis of persistent vegetative state is one that is abhorrent. It means that all higher cognitive brain functions or processes of thought and communication are gone. It means that only those body functions associated with the brain stem, that is, basic reflexes, remain."); *In re Fiori*, 673 A.2d 905, 908 (Pa. 1996) ("The term 'vegetative state' describes: 'a

contrary notwithstanding.²⁶⁴ Further, such an individual has no chance of returning to a conscious state.²⁶⁵

Certainly, it might seem that keeping someone in a permanent vegetative state alive until the family became reconciled to the patient's condition would be the least that one could do, especially because the treatment would hardly harm the patient.²⁶⁶ Yet, it would at

body which is functioning entirely in terms of its internal controls. It maintains temperature. . . . heart beat . . . pulmonary ventilation. . . . digestive activity. . . . [and] reflex activity. . . . But there is no behavioral evidence of either self-awareness or awareness of the surroundings in a learned manner." (quoting *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 267 n.1 (1990) (quoting *In re Jobes*, 529 A.2d 434, 438 (N.J. 1987) (plurality opinion))).

264. The American Medical Association's Council on Scientific Affairs and Council on Ethical and Judicial Affairs describes the plight of the PVS patient as follows:

Despite an "alert demeanor," observation and examination repeatedly fail to demonstrate coherent speech, evidence of comprehension of the words of examiners or attendants, or any capacity to initiate or make consistently purposeful movements. What movements do occur are largely confined to reflex withdrawals or posturing in response to noxious or other external stimuli. Since neither visual nor auditory signals require cortical integrity to stimulate brief orienting reflexes, some vegetative patients may turn the head or dart the eyes toward a noise or moving objects. However, PVS patients neither fixate on nor consistently follow moving objects with the eyes, nor do they show other than startle responses to loud stimuli. They blink when air movements stimulate the cornea, but not in the presence of visual threats per se.

Council on Sci. Affairs & Council on Ethical & Judicial Affairs, American Med. Ass'n, *Persistent Vegetative State and the Decision to Withdraw or Withhold Life Support*, 263 JAMA 426, 427 (1990) (footnote omitted). A commentator vividly describes PVS patients:

Patients in a persistent vegetative state are harrowing to behold. They present a much more disturbing picture than do patients in [a] coma, who appear to be sleeping peacefully. Patients in a persistent vegetative state seem to sleep and wake up as we do. They move, look around, make faces, and blink their eyes. The neurologists tell us that all this activity is pure reflex, that nothing is getting through to them. Yet, because we are so unaccustomed to the idea of a human body moving without a mind to guide it, we have difficulty convincing ourselves that the patient is not aware of herself and the world outside. The ambiguity invites observers to project their own needs and concerns onto the patient. Thus, the *Quinlan* justices, horrified at the premature interruption of a young woman's life, project their own sense of violation onto the insensate patient. The parent, mourning the loss of the daughter he once knew, bitterly resents the claim that anything of her is left in the unresponsive body that remains. And some of the nurses and doctors, whose own lives are significantly bound up with caring for brain-damaged patients, "see signs of intelligence where no such intelligence exists."

Dresser, *supra* note 114, at 642-43 (footnotes omitted).

265. See Smith, *supra* note 53, at 4 ("A patient diagnosed as being in a PVS has no chance of regaining consciousness or returning to a sapient existence.").

266. See Massie, *supra* note 201, at 204 ("Anyone suffering a total loss of consciousness is . . . not 'burdened' by invasive medical procedures, because, so far as we can ascertain, the patient has no sensations of pain and certainly no awareness of any dignitary interest at stake.").

best be ironic to allow psychological concerns to justify futile treatment, but not to justify possibly effective treatment that would provide a patient's only possible hope for survival. The implicit priorities of such a policy are simply unacceptable.

IV. CONCLUSION

In re Baby K brought the issue of medical futility to the nation's attention. Arguably, the case should be understood as an incorrect reading of the legislative intent behind EMTALA. This incorrect reading can be rectified by Congress's passing a clarifying amendment. Yet, the *Baby K* district court's reading of the ADA could have far-reaching implications for the concept of medical futility, because the court's interpretation would basically gut the concept.

The concept of medical futility must be robust enough to do more than just exclude treatments that would either have no effect or would be refused by the patient anyway. Given the advancements in medical technology and the possible opt-out provisions built into law, a failure to have a somewhat robust notion of futility may mean that individuals who are completely brain dead will be kept "alive" for weeks, or that individuals with no chance of having consciousness restored will be kept alive indefinitely.

Nonetheless, the tendency in the medical profession and society at large to undervalue the lives of those with disabilities militates against having a very robust notion of medical futility. Reasonable people may differ about what price is too dear for the possible extension of conscious life, and it would be inappropriate to imply that, for example, additional days of conscious life are simply of no value. Further, any justification for choosing a particular concept of futility must neither undermine patient autonomy nor imply that patients have the right to decide whatever they want, including, for example, the definitions of futility and death.

Futility discussions must be situated in the context of a society in which there are scarce resources and in which current treatment practices sometimes involve denying patients their only realistic chance of sustaining conscious life. The point is not that futility should be defined, even in part, in terms of available resources or the costs of treatment. Rather, the point is that no sensible policy would simultaneously hold that nonbeneficial treatments must be given if desired, but that possibly beneficial treatments may be withheld. To suggest that futility must be a patient-centered concept, but that individuals may permissibly be denied the only treatments that may save

their lives, is to endorse a counterintuitive and positively harmful policy.

Commentators must take seriously the notion that the focus of their views on futility—e.g., humanitarian concerns and a desire to support patient autonomy—must be reflected in other areas where treatment decisions are made. Otherwise, the view adopted may not only reflect an unwise policy but a position that implicitly undermines the value of human nature itself.